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MEDICARE ALZHEIMER'S DISEASE DEMONSTRATION EVALUATION

Final Report
October 1998

Prepared by

Institute for Health & Aging
University of California, San Francisco

Submitted to

lealth Care Financing Administration under contract number 500-89-0069
The authors remain solely responsible for the contents of this document.

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Preface

The Medicare Alzheimer's Disease Demonstration involved multiple communities and two variations of an expanded Medicare long term care benefit intervention. Moreover, at least five outcomes were used to evaluate the program's effectiveness. The demonstration was implemented with sufficient enrollment in each community to allow many questions to be addressed with a community-specific comparison of treatment and control group outcomes. These communities were, in turn, also aggregated into program models with comparisons conducted at that level as well. Another complexity was that Congress extended the demonstration twice after it had begun operation. This was done to help determine if the program's effects on caregiver outcomes, Medicare expenditures, and nursing home placement rates grew or diminished with extended exposure to the case management and community services available under the demonstration.

The demonstration was very successful in both the initial randomization of program applicants into treatment and control groups, and in being able to maintain comparably high cooperation levels among both groups over the three evaluation years. Equal care was taken in conducting the data analysis. To help assure this, the Health Care Financing Administration and the evaluators agreed to submit the project's analysis to both an internal HCFA review and to external review by anonymous panels selected by scientific journals. Chapters 2 thru 7 of this report contain the substantive findings from the evaluation. All but Chapter 7 have been through peer review and have been accepted for publication in scientific journals. Chapter 7, and Chapter 1 (a summary of the major findings) are still undergoing external review. Each substantive question required its own unique analytical approach, and each chapter fully explicates the methods used. The findings chapters are supplemented with appendices that, taken together, provide an extensive literature review into the health services research related to dementia, and explicate the demonstration and evaluation design and important implementation and technical assistance issues. Appendix 6 is a methodological paper addressing how Medicare claims were used to classify the health conditions of program participants. This was submitted to peer review and accepted for publication.

Acknowledgements

Foremost we acknowledge the families who participated in this demonstration. They did so with the knowledge that they had a fifty percent chance of being placed into a control group in which they would receive no added benefits from Medicare and the certainty of having the evaluators contact them every six months for an ensuing three years for data collection. More than 8,000 families agreed to do this. Almost two-thirds of this number would leave the demonstration before the end of three years because of the death or nursing home placement of the person with dementia for whom they were caring, but very few left the evaluation simply because they no longer wanted to be part of it. They all believed in helping others in situations similar to their own. As a tribute to this dedication we have tried to be explicit about those things that worked in the demonstration, and to examine why things did not work. We hope the findings are helpful for public policy decisions about the tested benefits, and for further understanding of how Medicare resources might be saved in other health care sectors in order to generate needed funding to meet the special needs of this population.

The demonstration sites program managers and staff are acknowledged for the positive spirit and dedication they brought to this endeavor. Without exception, they delivered the case management and home care services expected of them. We also thank our project officers, Nancy Miller and Dennis Nugent at the Health Care Financing Administration. They worked closely with us in the many adjustments needed to get the program operational and to accommodate the project's two extensions. They brought insight and humor to this process and to the many project meetings.

Principal Evaluation Staff

Robert Newcomer, PhD	Principal investigator
Patrick Fox, PhD	Co-Project Director
Cathleen Yordi, DSW	Co-Project Director
Anne Wilkinson, PhD	Field Staff Coordinator
Pamela Arnsberger, PhD	Case Management Consultant
Gina Donatonni, PhD	Data Coding Coordinator
Robert Miller, PhD	Senior Analyst
Ted Clay, MS	Statistician and Programmer
Richard DuNah, MS	Statistician and Programmer
Mark Spitalny, MS	Statistician and Programmer

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Chapter One

Lessons from the Evaluation of the Medicare Alzheimer's Disease Demonstration

By

Patrick Fox, PhD
Robert Newcomer, PhD

Institute for Health & Aging
University of California, San Francisco

The Medicare Alzheimer's Disease Demonstration and Evaluation (MADDE) was developed in response to Section 9342 of the Omnibus Budget Reconciliation Act of 1986. The demonstration's purpose was to test a Medicare-funded case management and community care benefit program targeted for persons with dementia.[1] The primary goals of the demonstration included: 1) ensuring the development of a network of community-based services that address the medical, mental health, and social support needs of persons with Alzheimer's disease and their caregivers; 2) providing education and support services to caregivers to minimize burden associated with caregiving and to enhance caregiving skills; 3) supporting the use of the most appropriate level of care whether in community or institutional settings and; 4) ensuring that the services provided were cost-effective. The Health Care Financing Administration (HCFA) was responsible for implementing the demonstration. MADDE operated in eight communities and began enrolling participants in December 1989 and remained operational through November 1994. This paper summarizes the findings from the demonstration evaluation.

Background

Most long term care for functionally impaired elderly people has been provided by informal caregivers, mainly family members (Shanas, 1979; Rivlin & Weiner, 1988). The National Long Term Care Informal Caregiver Study found approximately 2.2 million caregivers providing informal unpaid assistance to 1.6 million non-institutionalized frail elderly people (Stone, Cafferata & Sangl, 1987). Primary caregivers of frail elderly people spend, on average, four hours per day in caregiving activities. The number of people with Alzheimer's disease and related dementias is a substantial proportion of the aged population needing some form of long term care. An estimated four million American adults suffer from Alzheimer's disease or other forms of dementia (cf. Bachman, Wolf, Linn, et al., 1993; Evans, Scheer, Cook, et al., 1990), and it is estimated that about half of the nursing home population has dementia (Rovner et al., 1986).

[1] Additional legislation (Section 4164(a)(2) of the Omnibus Budget Reconciliation Act of 1990) eventually extended the demonstration until 1994.

Caregiving to those with dementia is known to be a challenging responsibility for family members (cf., Brody, 1989; Cohler, Groves, Borden, & Lazarus, 1989). This results from a combination of factors: the terminal nature of the illness which is preceded by the demented person's mental decline, loss of independence, and increasing need for supervision and assistance (e.g., Duijnstee, 1994; Vitaliano, Young & Russo, 1991; Dillehay & Sandys, 1990; Pallett, 1990; Malone Beach, Zarit, & Spore, 1992). Caregivers of people with dementia have often been found to experience depression, anger, anxiety, and guilt; and to report negative attitudes toward demented people and their family members (cf., George & Gwyther, 1986; Schulz, Visintainer, & Williamson, 1990; Schulz, Williamson, Morycz, & Biegel, 1993). The responsibilities of caregiving often constrain social participation, may necessitate withdrawal from the work force (cf., Scharlach, 1994; Scharlach & Boyd, 1989; Stone & Short, 1990), may disrupt family relationships, and can contribute to the deterioration of the caregiver's physical health. (cf., Zarit, Pearlin, & Schaie, 1993: Cafferata & Stone, 1989; Anthony-Bergstone, Zarit, & Gatz, 1988; Poulshock & Deimling, 1984; George & Gwyther, 1986; Pruchno & Resch, 1989; Zarit, Reever, & Bach-Peterson, 1980). These many negative effects contribute to a concept summarized as caregiver burden.

Caregiving assistance from other family members or friends can buffer or mediate the primary caregiver's response to stressful aspects of caregiving (Pearlin, 1990). Services provided by paid or formal providers, can also reduce the strain of caregiving by offering respite from this role. Disabled elderly people living in the community generally turn to formal care after their care needs become more than the informal care system can handle alone (Soldo and Manton, 1985).

The desire to assist families providing caregiving for those with dementia was a major influence on the Congressional mandate for the MADDE program. At the same time, policymakers continued to be concerned that publicly paid long term care could erode the unpaid informal care being received by impaired older adults (Congressional Budget Office, 1977; Health Care Financing Administration, 1981). An estimated 27 million days of unpaid care are provided each week in the U. S. (Liu & Manton, 1985).

While potential cost shifting from families to Medicare is an important public policy issue, there is evidence from prior studies of people with dementia showing that they "underutilize" formal care (Webber et al., 1994; Bass et al., 1992; Biegel et al., 1993; Caserta et al., 1987). Underutilization refers to the difference between a professional assessment of an individual's need for formal assistance compared with the level they are actually receiving. Among the explanations for under use of services is a general unwillingness of caregivers to seek formal assistance. This reticence may arise in part from the social stigma associated with dementia, the shortage of available formal providers that are willing and/or able to accommodate people with dementia (Hooyman et al., 1985); and the hassle-factors experienced when bringing providers into the home that reduces the acceptability of in-home services to the consumer (Ory et al., 1985). Additionally, some families cannot afford this assistance (Haley et al., 1987).

MADDE was designed to address each of these underlying factors, to facilitate access to community care, to test whether access to service benefits reduced caregiver burden, affected the level of informal care, and whether expansion of Medicare coverage for community care was offset by savings in the other Medicare covered health care costs. Unlike earlier community care demonstrations, there was no expectation that MADDE would reduce nursing home admission rates or delay nursing home admissions. Consideration was given, however, to the likelihood that the provision of case management services might facilitate the decision by caregivers to institutionalize a demented person if that was the appropriate level of care required due to the demented person's physical and mental condition or the caregiver's condition.

Demonstration Design

MADDE was a five-year demonstration designed by Mathematica Policy Research, Incorporated. Evaluation of the demonstration was conducted by the Institute for Health & Aging at the University of California. Demonstration features included a reformulation of features used in prior long term care demonstrations: case management, a monthly per-client reimbursement cap, and a 20 percent client copayment. Unlike other long term care demonstrations, the MADDE intervention was mainly designed to support the primary caregiver and the informal care network,

and secondarily the person with dementia. The case management intervention was designed to: 1) link caregivers with appropriate and acceptable community-based formal services; 2) provide psychological support to caregivers; and 3) insure that monthly per-client cost caps were not exceeded. The reimbursement feature was designed both to provide financial resources for the provision of formal services to augment the informal system, as well as a cap on the monthly per-client dollar amount for which the Medicare program would pay. The copayment was implemented as a cost control measure under the assumption that demonstration participants would be less likely to unnecessarily use services if they were required to pay for a portion of service costs.

The demonstration enrolled participants that met four criteria: 1) diagnosis of irreversible dementia; 2) enrollment in Parts A and B of the Medicare program; 3) residence in the demonstration site's catchment area; and 4) living in the community at the time of application to the program. Enrollment into the demonstration occurred between December 1, 1989 and November 30, 1991. Eligible applicants at each site were randomly assigned into treatment and control groups after an initial screening interview.[2] A total of 8,095 beneficiaries were enrolled. Demonstration site agencies could provide case management and subsidize direct services to clients for the duration of the project, if the client remained in the community. Clients were disenrolled from the demonstration services 60 days after they permanently entered a nursing home.

Two Models were tested in the demonstration. Model A sites (Rochester, NY; Urbana, IL; Memphis, TN; and Portland, OR) and Model B sites (Cincinnati, OH; Parkersburg, WV; Minneapolis, MN; and Miami, FL) offered the same set of services. These included adult day care; homemaker, housekeeping; general chore (i.e., heavy cleaning); personal care; minor home repairs; companion services; non-emergency transportation; adaptive and assistive equipment; consumable care goods (such as for incontinence); and safety modifications to the home.[3] Model A sites had a 1:100 case manager to client ratio, while Model B sites had a 1:30 ratio. Model A

[2] This randomization produced equivalent groups at enrollment. There was no differential attrition due to death, disenrollment, or loss to follow-up over the three years of data tracking. (See Chapter 6 for a full discussion of the tests of enrollment and attrition differences.)

[3] Additional, but seldom used, services included skilled nursing and rehabilitation nursing therapies (i.e., speech, occupational, physical; home health aide), medical supplies in conjunction with skilled and unskilled home care, and home-delivered meals not otherwise reimbursed by Medicare.

clients could use a $290-489 monthly benefit, whereas Model B clients had a $430-699 benefit. Per month reimbursement caps in each model varied by site due to regional cost differences and over time due to inflation adjustments. In both models, clients paid a 20 percent copayment (i.e., a 20% coinsurance rate) for demonstration subsidized services. Case management and caregiver support services were covered by the program's administrative budget and were not included under the client's monthly expenditure caps. The support services included caregiver education and training, caregiver support groups, mental health and counseling services, and transportation to education and support groups. Care usually covered under Medicare continued to be reimbursed as part of the beneficiary's regular Medicare benefit.

The eight sites differed from each other in important ways, including their long term care service environments, urban/rural and race/ethnicity composition, and case manager activity mix.[4] For example, sites in New York, Oregon, Florida, and Ohio operated in well-developed home and community-based service environments, whereas the sites in Illinois, West Virginia and the rural areas of Tennessee and Minnesota did not. One site (Minneapolis) had over twice the number of nursing home beds per thousand persons 75 and over than did another (Memphis). Although all sponsoring agencies were located in cities, urban/rural composition varied because four sites included rural counties in their catchment area. Race/ethnicity composition also varied substantially among sites. Although "non-Hispanic whites" accounted for about 95 percent of participants in 5 sites, African-Americans accounted for one-third of participants in Tennessee and 15 percent of participants in Ohio. Hispanic whites accounted for one-fifth of the participants in Florida.

Each site agency implemented the demonstration in somewhat different ways. For example, the Illinois program employed nurses as case-managers, whereas other sites employed social workers. Overall, site agencies made little attempt to integrate formal and informal long term care services with medical services. Only in Illinois did nurse case-managers attempt to specifically intervene to alter the pattern of medical care. Organizational arrangements among site agencies also varied widely. Some agencies provided services through their own home care

[4] See Appendices 4 and 5 for a full discussion of these community and implementation attributes and Chapter 2 for an analysis of case manager activities.

departments whereas others contracted out for services. This affected the training of formal caregivers. All sites conducted or arranged for some agency staff training, the training activities varied when agencies contracted out service provision.

Demonstration Effects

The principle findings related to the demonstration's major policy questions are summarized here:

- clients' informal support systems,
- the use of community-based services,
- primary caregiver burden and depression,
- regular Medicare service use, and
- client institutionalization rates.

Effects on Clients' Informal Support Systems. Perhaps the most important policy question is whether the demonstration reduced the amount of informal caregiving in favor of increased use of formal or paid care. This issue was assessed at six months, annually, and over multiple years. At all such intervals, there was no evidence of any difference between those in the treatment group and the randomized control group in the total hours of care provided by either primary or all informal caregivers. There also was no difference in the average number of tasks for which caregivers provided support to their family member for either activities of daily living (e.g., ADL; bathing, dressing, transferring, toileting, and eating) or instrumental activities of daily living (e.g., IADL; grooming, housekeeping, shopping, transportation). In spite of the absence of differences in hours or caregiving tasks, those in the treatment group reported about 50 percent fewer tasks in which they had an unmet need for assistance in their provision of support. This program effect emerged within the first six months after enrollment and continued throughout program participation. One explanation for the difference in unmet task assistance needs is that those in the program were more likely to have used formal care to replace IADL activity and to focus more of their own efforts in ADL support. (Chapter 3 elaborates these findings.)

Effects on the Use of Community-Based Services. The use (42%) of community-based services was relatively widespread among the MADDE sample at baseline and increased over time (to 75% among those in treatment and to 57% among the control group). Even with the general increased use, the likelihood of using home care (e.g., homemaker/chore, companion, or personal care) was 2.8 times higher and the likelihood of using adult day was 2.6 times higher among those in treatment group relative to the controls. Among those using services, there was no difference between the treatment or control groups in the amount of services used (i.e., days of day care, or hours of home care). In other words, people who were paying for services out-of-pocket, on average, had levels of service that were similar to those who had access to the expanded Medicare benefit. It appears that the expanded Medicare benefit, which provided services at 80 percent price reductions, was primarily used by the treatment group as a substitute for private payment, rather than as a supplement allowing more units of formal care to be purchased.

Service use patterns varied by community and by model. The lower monthly payment program (i.e., Model A sites) gave more emphasis to home care, the higher resource programs (i.e., Model B sites) were somewhat more likely to emphasize adult day care. (Chapter 4 further discusses these findings.)

Effects on Primary Caregiver Burden and Depression. The effect of case management and community care support on caregiver burden and depression is one dimension of MADDE that had not been thoroughly examined in other major prior long term care demonstrations (cf., Weissert, Cready, & Pawelak, 1988; Kemper, Applebaum, & Harrigan, 1987). On average, caregivers in the MADDE program had scores on burden and depression scales that were below levels considered to be clinically problematic. In spite of this, participants in a subset of MADDE sites were found to have had statistically significant, but small, reductions in caregiver burden and depression. These results were persistent whether measured at six months, one year, or across all three years of the evaluation follow-up period. Particular subgroups of caregivers, such as those who had depression scores defined as suggestive of clinical depression at baseline, showed no major difference in treatment effect than the average demonstration enrollee. Treatment and control

group differences were not statistically significant when all sites were considered together, nor was there any particular advantage to the higher resource Model B compared to Model A in terms of affecting caregiver burden and depression. (Chapter 5 further discusses these findings.)

Effects on Regular Medicare Service Use. For the demonstration to be budget neutral the community care services and case management expenditures must be offset with substantial reductions in hospital, physician, or other Medicare covered health expenditures. Annualized Medicare expenditures were compiled for the first year after demonstration enrollment, each single year of demonstration participation, and with all periods combined. Medicare Part A expenditures (primarily hospital and skilled nursing home expenses), and Part B (primarily physician) expenditures were considered both separately and combined. Under the assumption that the treatment intervention may be preventative for some acute care problems (such as those reflective of Part A payment for hospital or emergency room use), the distinctions in time and coverage made it possible to assess any short and extended term differences that may have occurred between the treatment and control group. Given the historical tendency for dementia patients to under use health care services, it was less certain whether the demonstration would increase or decrease rates of physician use over the short term and more extended intervals. Treatment group members, pooling all sites together, were found to have significantly lower Medicare Part A expenditures (after one year) and lower combined Medicare Part A and B expenditures (over 2+years), than persons with comparable health status in the control group. These differences were not uniform among all sites. In general, most of the expenditure differences among the treatment group were found in just two sites, both of which happened to be in Model A. The average annual savings or difference between the treatment and control group expenditures was about $500 in all periods and in year 1. These savings were not large enough to offset the per member cost of case management and the monthly home care benefit expenditures. Even in sites with Medicare Part A and or Part A & B savings, total expenditures were usually about $2,000 short of the reductions needed for the demonstration to approach budget neutrality. (Chapter 7 discusses the expenditures analysis.)

Effects on Institutionalization Rates. While not a programmatic focus of the demonstration, there nevertheless was interest in whether the demonstration's success in reducing unmet task assistance need, increasing access to community care, and reduced hospital costs was reflected in reduced or delayed nursing home placement rates. The effect of the demonstration on client institutionalization rates was comparable to that found in other community-based long term care demonstrations, namely, the provision of case management and community services was not sufficient to change the rates of nursing home entry or to delay institutionalization. Furthermore, there was also no advantage to the higher resource model in terms of affecting these rates. (See Chapter 6 for a full discussion of these findings.)

Discussion and Conclusions

Overall, the results of the Medicare Alzheimer's Disease Demonstration reaffirm findings from prior community-based long term care demonstrations. The interventions tested did not reduce caregiver hours. They increased access to community care, but they did not reduce rates of nursing home placement. The program produced statistically significant, but not programmatically significant, reductions in caregiver burden and depression, and in Medicare expenditures. The higher monthly benefit cap 1:30 client to case manager program failed to show any programmatic advantage over the less expensive 1:100 client to case manager program. Even the 1:100 demonstration model program would need either substantial reductions in operating costs or extensive further reductions in Medicare expenditures to be a budget neutral program.

Taken together, the findings suggest that the current informal care networks provided a level of care to demented beneficiaries that was roughly equivalent to that received by those enrolled in the demonstration. While there may be unmeasured dimensions of the intervention's benefit to its members, it appears that the members of informal support systems make adjustments which enable them to sustain a viable level of capacity over extended caregiving periods.

It is informative for public policy and further research to consider why the demonstration did not produce more measurable benefits for its enrollees. One explanation seems to lie in the fact that the level of the community care coverage available in MADDE did not increase overall average

formal service use among those using the services. In otherwords, the program benefits appear to have largely replaced care that could have (or would have) been purchased with out of pocket payments. Whether more intense (e.g., 16 or 24 hours of care per day) or focused service use (e.g., during a health care crisis or after a hospital placement) could have produced different results was not tested within this program.

A second possible explanation for the few striking program effects may arise from limitations within the demonstration design itself. For example, subgroups like whether the caregiver was a spouse, a daughter, or other relative were statistically controlled for in the demonstration analyses, but these groups were generally not large enough to determine if there were particular risk factors for depression, burden, nursing home placement, or health care expenditures within these subgroups that could have been responded to by the case managers. As one begins to consider methods for how to target or focus case management and community care benefits for those with dementia there are two subgroups of particular interest for further work in this area: persons in health care or other crises, and families that have recent vs. extensive months of experience in their caregiving rolls. MADDE enrolled <u>any</u> eligible dementia applicant, and did not deliberately recruit or select applicants across a continuum of experience such as suggested here. A third subgroup of interest would be persons with "near poor" income levels. MADDE largely excluded applicants who were receiving Medicaid. This was done to minimize the confounding of the treatment and control groups when either or both could be receiving Medicaid reimbursed case management and community services. In general, Medicaid coverage was much more extensive and comprehensive than that available from MADDE. Persons with low, but not poverty incomes (such as between Medicaid eligibility and a community's median income), were accepted into the program on a first come first served basis with all other income levels. A net effect of this is that the near poor subgroup of enrollees was not large enough to separately evaluate the experience of its caregivers with those in the control group of similar income. It could well be that near poor populations benefited more from MADDE's service coverage levels than did those with higher incomes.

A third area for further research is suggested by the interesting and unusual finding of a substantial reduction in the treatment group member's perceived unmet need for client ADL/IADL task assistance. This seems to be related to a tendency among those in the treatment group to substitute formal care for IADL assistance and to focus more of their activity to ADL tasks, but how much of this is reflective of the assistance from case managers? How much may be related to a placebo effect or a sense of psychological security arising from the knowledge that the family could call upon their case manager and could have access to reduced price services if they were needed? The demonstration design did not allow caregivers to save up or accumulate their monthly benefits for more intensive uses at a later date. Would such a program feature heighten the sense of security? The relative influence of possible perceptual "safety net" features from program benefits and case manager support have not received previous research attention.

The failure of the demonstration to reduce hospital and physician Medicare expenditures enough to approach budget neutrality for the demonstration services also deserves further exploration. Foremost, it is important to note that this finding is based on analysis only of MADDE treatment and control group members who received their health care in fee for service health systems. Due to data limitations in the Medicare program, service encounters and claims are not compiled for beneficiaries enrolled in capitated health plans. One immediate consequence of this is that the performance of MADDE in a managed care environment has not been tested. A second limitation on the finding relative to Medicare cost savings is that the demonstration was not expressly designed to integrate acute and long term care financing or service delivery. The demonstration had no direct control (or financial risk) over medical or other health-related interventions that may have prevented acute episodes leading to either hospital stays or institutionalization. Moreover, the programs were not operated in connection or in collaboration with a client's primary care provider. Extensions of the MADDE covered benefits, in combination with a coordination with primary care management may produce Medicare expenditure results substantially different from the reported findings. This could occur, for example, if such service integration results in a better ability to assess changes in health status and to respond to health

crises earlier and more rapidly. Complementing this coordination, it may be that case targeting can be more efficient and that coverage could shift, or extend to include an emphasis on expanded care for short-term crises and/or transitional situations.

A fifth issue is the absence of a demonstrable effect on institutionalization rates in spite of treatment effects on community service access and caregiver task assistance. While this finding is consistent with the vast majority of community-based long term care demonstrations (cf., Weissert & Cready , 1989; Weissert, et al., 1988), including the Channeling demonstration which included community care coverage equivalent to 60 percent of the monthly cost of a nursing home stay, it remains perplexing. Case management and even routine community care, by themselves, do not appear to be sufficient to reduce nursing home placement likelihood. Not directly tested by this demonstration is the relationship of case management to other health condition risk factors for nursing home placement. The analysis of Medicare expenditures revealed increasing health care expenditures in the weeks preceding nursing home placement. This suggests that changes in health status may contribute to placement. The intervention, as noted above, was not designed or implemented with health care coordination as an operational feature. Any reformulation of a MADDE intervention should consider how case management could support disease management and whether such involvement reduces the likelihood of hospital stays and subsequent nursing home placements.

A final area for consideration is the client to case manager ratio. MADDE found no evidence that the higher resource Model B intervention was better in affecting the desired outcomes than the lower resource Model A intervention. In light of this and the substantial reductions in program costs needed to make even the lower resource model budget neutral for Medicare coverage, it seems appropriate to consider further work to determine cost effective case loads. Such endeavors are complicated by ambiguity about what the roles and functions of case managers should be. The design of this demonstrations and its predecessors placed inherent constraints on the time potentially available to care managers to perform their functions. These included protocols requiring uniformity in the process and frequency of client assessments, care planning,

reassessments, care monitoring, and service management. Future demonstrations should consider giving programs more latitude in determining the frequency of scheduled client contacts and in varying their procedures according to the client's risk group. Case manager to client ratios of at least 1:200 may be needed to make the cost of the case manager intervention affordable. Such case loads will necessitate more differentiated client targeting and monitoring than have been permitted in prior demonstrations.

In summary, the Medicare Alzheimer's Disease Demonstration and Evaluation achieved a number of its goals, but showed mixed results in its usefulness to informal support systems. Access to community care increased by more than a factor of two and the level of unmet task assistance in caring for the person with dementia was reduced by half among those in the treatment group. These supports generally did not replace the amount of informal care, instead they allowed this time to be redirected to specific tasks. These instrumental program achievements did not lead to significant reductions in caregiver burden or depression, nursing home placement rates, or overall Medicare expenditures; nor was the intervention budget neutral. Questions were raised as to whether these outcomes are the most appropriate criteria for assessing the efficacy of the case management and community services benefit. For example, the prevailing level of burden and depression among MADDE caregivers was generally below thresholds that clinically define someone as having actionable conditions. Similarly, the risk of nursing home placement seems to be connected to a variety of factors, including health status, that are outside the traditional role of community case management interventions. A closer connection of case management, community support, and primary health care may produce effects on preventable health care episodes. This was not an explicit purpose of this intervention, but it reflects a logical extension of care coordination. The clinical efficacy of treatment targeting for high risk cases defined in terms of health conditions or caregiver capability warrants further investigation, particularly in a managed care context. Finding a high risk case does not by itself assure that an effective care plan can be designed or implemented. Exploration of possible modes of communication and collaboration

between caregivers (whether family members or paid providers) and care managers, and between care managers and health care providers also warrants further attention.

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Chapter 2

TREATMENT GROUP CASE MANAGEMENT IMPLEMENTATION: CASE MANAGER ACTIVITY, CLIENT RISK FACTORS, AND SERVICE USE

By

Robert Newcomer, Ph.D.[1]
Pamela Arnsberger, Ph.D.[2]
Xiulan Zhang, C.Phil.[3]

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[1]Professor, Department of Social and Behavioral Sciences, University of California, San Francisco.

[2]Assistant Adjunct Professor Institute for Health and Aging, University of California San Francisco, San Francisco.

[3]Doctoral Candidate, School of Social Welfare, University of California, Berkeley.

Abstract

Six "pure" types of case manager activity are identified using chart data from 922 cases in the Medicare Alzheimer's Disease Demonstration. The association between case manager actions and client characteristics, and between case manager activities and service use outcomes is used to test predictive validity. Case manager activity is generally more associated with caregiver than client characteristics. Monitoring and service management was protective against nursing home placement. A clinical nursing emphasis was protective against hospitalization. Few differences in case manager activity emphases were found within the 1:30 and 1:100 case manager to client ratios tested by the demonstration.

The term "case management" has come to describe a method of organizing a fragmented group of service providers (and sometimes funding sources) at the point of service delivery. One impetus for the initial growth in this approach was the expansion in community-based care options for persons needing some form of long-term care (Weil & Karls, 1985). Case managers in these programs may determine benefit eligibility and develop care plans for those electing to remain outside of nursing homes. On a more limited scale, case management functions have begun to be extended to the interface between acute care (and even primary health care) and a multitude of community care services. Community services include skilled care such as home health and nursing homes, as well as "nonskilled care" such as residential care, day care, meals programs, and homemaker/chore services. Case management in this context can range from simple referrals to serving as a point of information coordination between multiple providers. The incorporation of case management into health care delivery is being stimulated by (a) the recognition that large numbers of elderly with chronic conditions require treatment that is inappropriate for acute care settings; (b) funding for in-home and community-based care from Medicaid waiver programs; (c) advances in medical practices that have resulted in many types of medical and surgical care being practiced outside the hospital in community-based or home settings; and (d) recognition of communication problems between primary care providers and medical specialists and other providers (Austin, 1990; Mor, Piette, & Fleitmann, 1989; Rothman, 1992).

Case management is now considered a pivotal component of long-term care service delivery and as a likely adjunct to primary care in managed health care systems (Grower, 1997; Kane, 1985). Inpatient and nursing home case management teams may also be gaining prominence. The utility of case management is based more on its face validity than on scientifically documented success. The two major evaluations of community-based case management interventions, the Channeling demonstration (cf., Kemper, 1990) and the Medicare Alzheimer's Disease Demonstration (cf. U.S. Department of Health and Human Services, 1992), as well as a number of other demonstrations using case management as part of community-based long-term care services (cf., Berkeley Planning Associates 1986; Kemper, 1988; Kemper, 1990;

Mathematica, 1986; Weissert, 1985; Weissert, 1988) have generally failed to find a cost savings resulting from case manager interventions. These programs, particularly those able to reimburse community services, have shown that they can improve access to and use rates of community care.

Several studies conducted in Great Britain have found a therapeutic benefit. As early as 1970, British researchers concluded that the provision of support services to families of elderly people with dementia enabled them to cope longer and thus maintain elders at home (Sainsbury & Grad de Alarcon, 1970). More recently, community-wide studies in townships such as Gloucester, East Kent, and Edinburgh showed that through early intensive case management efforts, the number of geriatric hospital admissions was reduced by as much as 60 percent, hospital stays were shorter, and the probability of admission to residential care declined substantially (Barker, 1985; Davies, 1988). Anecdotal studies that measure caregiver burden and satisfaction with services have also produced positive findings (Gilhooly, 1984).

In focusing on variables predicting positive outcomes, British researchers (unlike the U.S. studies) were led to examine the "core tasks of case management" and concluded that "the importance of recognizing the core tasks is that their performance directly affects most aspects of efficiency" (Davies, 1988, p. 4). The British literature reflects attempts to delve deeper into the multidimensional, managerial, coordinative, and clinical functions of case management. Factors identified that may affect case management service outcomes include the professional background of case managers, the manner in which objectives are established and priorities set, the degree to which case managers have control over finances, the organization of their ongoing tasks and daily activities, and the implementation of a brokerage or consolidated model of case management (Davidson, Moscovice & McCaffrey, 1989; Malone Beach, Zarit & Spore, 1992).

Faced with the inconsistent findings about case management effectiveness and the continuing expansion of this function throughout the health and long-term care delivery system in the United States, emergent studies of case management have begun to give more attention to specific case manager practices. This has taken several forms. One approach is to delve into the professional background, managerial, coordinative, and clinical functions of case management, as

has been done in Britain. Others approaches measure connections between client characteristics and case manager's actions, and the resultant outcomes of this interaction (cf., Cambridge, 1992; Davies, 1988; U.S. Congress Office of Technology Assessment, 1990).

This paper follows this latter approach using case manager chart data to chronicle case manager activity. The purpose is to first create a typology of case manager activities, and then to explore the extent to which different types of case manager actions are related to client characteristics, and to assess the extent to which these actions are related to client and caregiver service use outcomes. This work has both methodological and practical applications. Current practice, particularly as prescribed in the demonstration programs cited above, constrain the discretionary behavior of case managers and require that certain segments of time be obligated to routine tasks. The emphasis given to a particular client by a case manager is usually unmeasured in most studies because case management is treated as an undifferentiated activity. Such bundling implicitly treats every contact as being equivalent. An unbundling of activity and contacts provides an opportunity to more specifically match activity and need, and to track some of the consequences arising from the encounters. Understanding when and how case management is differentiated, and the client and staffing consequences of this differentiation, should be helpful in designing case management programs, treatment protocols, and in gaining more sensitive measurement of case management program performance.

Case Management Tasks and Functions

Whether in the fields of mental health, health care, rehabilitation, AIDS, or aging, case managers typically perform a common set of sequential and often overlapping functions (Rothman, 1992). These generally comprise a subset of the following seven tasks (see Applebaum & Austin, 1990; Cambridge, 1992; Capitman, Haskins and Bernstein, 1986; Geron & Chassler, 1995; Piette, Fleitmann, & Mor, 1992).

- Screening and case finding involves eligibility determination and may be based on cognitive and functional status, geography, financial eligibility, and less often, the lack of available informal support
- Comprehensive assessment involves collecting in-depth information on client needs and

resources using a systematic protocol. Baseline demographic information is obtained, and the protocol may be used to determine a person's social situation, physical, mental and psychological functioning, and financial resources. An early ideal was to have a multidisciplinary team involved in the assessment; in reality. More typically, one individual completes the assessment, and consultation is available from other professionals to help translate the assessment into a care plan.

- Care planning's core objective is to identify resources for each area of need identified during the assessment and define the process by which clients are linked with those resources. The care plan should be revised based on additional information that may be acquired during the course of the care, especially at reassessment.

- Service coordination is required for implementation of the care plan and involves identifying a complex set of activities to meet each of several need areas and coordinating providers to meet those needs. Activities range from making referrals, to assisting the client and or caregiver in acquiring services, to making arrangements with vendors concerning the type and amount of service and authorizing payment for the services

- Monitoring is characterized by phone contacts and home visits to monitor the quality of care provided by vendors in the home on a routine basis

- Reassessment should occur at regular intervals, although the length of the interval is dependent on client characteristics and needs. An interval of six months is considered the average for long-term care case management. Reassessment may also be triggered by events in clients' or caregivers' lives or changes in client status, such as the death of the caregiver or a major hospitalization.

- Planned discharge is rarely indicated for community-based long-term care clients. However, discharge planing is often a necessary process when funding for case management is tied to a specific service (e.g., Medicare certified home health care) if it is connected to placement of the client in a nursing home or assisted living, or in relation to a hospital stay.

Although each of these functions is likely to be performed by case managers at some point with each client, there may be a wide degree of latitude about how these tasks are implemented, and even in whether a single case manager provides all these functions. Case managers may also have direct service roles, such as client and caregiver training in the use of assistive aids or equipment, or in how to access other community resources.

Another source of variation among programs and case managers is how they implement their roles. For instance, reassessment intervals may vary, as do the criteria that may trigger a reassessment, or the protocols that determine how data are collected. Care planning, such as a decision to institutionalize the client, is another source of variation--one that is further influenced

little discrimination.

Client functional status and caregiver attributes provide dimensions with some apparent relationship to case manager activities. Limitations in activities of daily living (ADLs) were positively associated with routine monitoring and negatively associated (although with a small coefficient) with most of the other approaches. Having unmet assistance needs for instrumental activities of daily living (IADL) tasks had a minor association with two of the factors. Caregiver attributes showed more risk factor variation. IADL limitation among caregivers was an important covariate for four of the factors, while ADL limitation (much less common in the caregiving group) was positively associated with only one. Depression, an assumed risk factors for caregivers, had a demonstrable relationship with factor 1 (negative) and factor 6 (positive). Issues related to the maintenance of employment status, affecting almost half the caregivers and a targeted risk of the program, were not a striking covariate for any factor. The size of the social support network and caregiver relationships are two dimensions that seemed to help trigger a case manager response. Larger networks were associated with factors 1 and 6. Routine monitoring was less likely when the caregiver was a not the spouse or the child of the client. The crisis intervention approach was more likely when other relatives or nonrelatives were the caregivers. The client to case manager ratio features of the demonstration were systematically associated with two approaches: factors 4 and 6 were somewhat more likely among those in the 1:100 model, although much of this relationship is tied to the Illinois site which (as noted previously) used only nurse case managers.

Case Management Models and Service Use

Logistic regression models were estimated to test multivariate comparison of each factor with selected service use outcomes. The analyses used the baseline client and caregiver attributes (shown previously in Table 2-2) as control variables. These were included in equations where all case manager "pure" type factor scores were used as the independent or predictor variables. The dependent variable was the presence or absence of a service use during the 6 month period following baseline. Separate sets of equations were calculated for each of the seven services shown in Table 2-5. For parsimony in presentation, the odds ratios for each case manager factor have

taken from each of these seven separate equations and summarized into Table 2-5. The odds ratios (OR) show the likelihood of use during the client's first six months after enrollment, controlling for client and caregiver characteristics. Values for the covariates are not shown.

Insert Table 2-5 About Here

In interpreting the relationships between case manager types and service outcomes, it is important not to infer cause and effect, since case manager activities could take place in response to temporally specific changes in status which are not captured in the static measures of client and caregiver characteristics (collected only at six month intervals in this project) controlled in the analysis. Moreover, case manager activities are not completely independent of the tasks needed to carry out certain services--most particularly the management of services in place. With these qualifications, the service outcomes analyses suggest a pattern of relationships that is much more discriminating among the case manager activity types than was true of the relationship between the measured client and caregiver attributes.

The activity of routine monitoring (factor 1), as might be expected, is statistically and positively associated with the demonstration's funded home care benefits: homemaker, companion, and personal care. It is also associated with persons receiving nursing services. Adult day care, alone among the demonstration funded benefits had no significant relationship to any case manager pure type. Caregiver training (factor 2), while not significantly associated with "hands on" direct services, is less likely to occur when companion services are used. This relationship is consistent with an assumption that companion service clients tend to be less characterized by behavioral and other problems that may require caregiver training. Crisis intervention (factor 3) is a counter image of routine monitoring, with a reduced likelihood of companion and homemaker use. Factor 4, the clinical nursing and caregiver support activity, parallels factor 1 in having a positive relationship to personal care use, but it has a reduced likelihood of homemaker services. Caregiver empowerment (factor 5) has a reduced likelihood of homemaker services and no relationship to the other services. Client health and placement activities (factor 6) is related to a reduced likelihood of one community service and has no significant relationship to the others.

Nursing home placement and hospital services, the remaining services in Table 2-3, reflect two different dimensions of the demonstration program's operations. An explicit purpose of the demonstration was to reduce nursing home placement. Hospitalizations, on the other hand, were seen as being outside of the case manager's control. Only three case manager activity factors have statistically significant relationships with health care use. Routine service monitoring, the predominant mode of case management, was associated with a lower likelihood of nursing home placement. Clinical nursing was associated with a lower rate of hospital admission. Client health and placement activity was associated with higher likelihood of hospital use. In this case, the direction of effect is very likely to be that the case manager is responding to these situations rather than causing them.

Discussion and Conclusions

The unbundling of case manager activity into component parts is intuitively appealing for program evaluation, since it may provide a more sensitive comparison of client outcomes relative to the assistance needed and given than a simple measure indicating participation in a program. It can be argued that in practice, this tailoring of activity to need is routinely done. The analytical challenge addressed by this paper is how to document and represent these multifaceted activities in evaluative studies. The approach taken was to create a profile of the types of case management activity received by a sample of clients, where each client's exposure to case management was weighted or distributed among the varying types of activity that occurred during a six to twelve month enrollment period. Six pure types of case manager activity were identified, with routine service monitoring being the most common function. Among the variables loaded on this factor were conducting baseline and semi-annual assessments, revising care plans, maintaining ongoing contact with service providers, and monitoring problems with service providers. These are the predominant activities around which MADDE (and most community-based case management demonstrations) are designed. The case managers reviewed in these analyses were expected to follow a regular protocol of client contacts (e.g., quarterly or semi-annual home visits, monthly phone contacts, and other contacts as needed), and assist them in using the program's community

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Figure 2-1

A Typology of Case Manager Activities

1. Routine service monitoring. Variables that loaded heavily on this factor included conducting a routine assessment, care plan development and revisions, maintaining ongoing contact with service providers, and monitoring problems with service providers.

2. Caregiver training/mental health approach. This factor was characterized by activities such as provision of disease management information to the caregiver, caregiver training on behavioral management, training to meet ADL and IADL needs, mental health counseling and therapy

3. Crisis intervention model. Activities characterized by this factor included a crisis assessment, obtaining health services assistance, and referrals to adult protective services and other crisis interventions.

4. Clinical nursing/caregiver support. Variables that loaded heavily on this factor included having an RN assessment, need for ongoing service adjustment, providing general caregiver support, and assisting caregivers in getting to a support group.

5. Caregiver empowerment/advocacy approach. This factor was characterized by assistance in obtaining non-demonstration-funded social services, referrals to non-demonstration support groups, and use of public guardian services.

6. Client health and placement approach. Discharge planning and placement assistance were variables loading heavily on this factor. Base/6

Table 2-1: Descriptive Statistics of Case Management Data Set

Variables	Sample Size	Mean Value[1]	Standard Deviation	Minimum Value	Maximum Value
RN assessment	922	0.299	0.748	0	5
Crisis assessment	922	0.037	0.253	0	5
Non domain assessment	922	0.025	0.188	0	3
Routine assessment	922	1.917	2.066	0	19
Care plan development	922	1.333	1.558	0	15
Care plan revision	922	1.243	2.487	0	25
Care plan problem solved	922	0.076	0.324	0	3
Service provider contact	922	1.923	2.158	0	16
Ongoing service adjustment	922	2.917	5.340	0	43
Routine monitoring	922	4.287	7.121	0	56
Change service provider	922	0.310	0.837	0	8
Quality problem solved	922	1.107	3.395	0	49
Monitoring per caregiver request	922	0.975	2.948	0	33
Placement discussed	922	0.677	1.280	0	11
Placement assistance offered	922	0.166	0.683	0	11
Discharge planning	922	0.101	0.491	0	6
Referred legal services	922	0.156	0.547	0	5
Referral non demonstration social services	922	0.176	0.723	0	9
Entitlement assistance	922	0.298	0.995	0	14
Health service assistance	922	0.288	1.086	0	11
Advocacy assistance	922	0.133	0.636	0	7
Referral non demonstration support group	922	0.196	0.844	0	20
Referral demonstration support group	922	0.552	1.325	0	10
Assist caregiver in getting to support group	922	0.253	1.463	0	28
General caregiver support	922	1.992	3.540	0	36
Non demonstration caregiver counseling	922	0.081	0.538	0	12
Disease information to caregiver	922	0.776	1.423	0	20
Caregiver ADL training	922	0.374	1.086	0	15
Behavior management to caregiver	922	0.409	1.140	0	12
Caregiver change activities	922	0.093	0.445	0	5
Client social skills training	922	0.616	2.019	0	40
Client depression counseling	922	0.053	0.303	0	3
Client mental health counseling	922	0.038	0.259	0	4
Therapy/intervention	922	0.068	0.412	0	7
Case manager/client therapy	922	0.068	0.474	0	7
Home environment modification	922	0.306	0.947	0	1
Client medications changed	922	0.154	0.571	0	7
Crisis referral	922	0.036	0.401	0	11
Obtained crisis services	922	0.027	0.193	0	2
Contacted public guardian	922	0.020	0.218	0	5
Contacted Adult Protective Services	922	0.114	0.962	0	24
Case manager medical consultation	922	0.744	2.558	0	60

[1]All variables are based on a count of the event or activity named in each row.

Table 2-2: Descriptive Statistics of Client and Caregiver Assessment Data

Variable	Sample Size	Mean or %	Standard Deviation[1]
Client Variables (Baseline)			
% Mild MMSE score (score = 25-30)	893	11.3%	
% Moderate MMSE score (score = 17-24)	893	42.8%	
Behavior problems (count = 0-19)	890	7.881	3.991
% Left alone safely (yes/no)	883	47.1%	
ADL impairments (10 measures, each 1-3)	891	18.004	5.826
Unmet ADL needs (count of yes on 1-10 items)	893	8.656	2.245
Unmet IADL needs (count of yes on 1-8 items)	893	6.996	1.606
Caregiver variables (Baseline)			
Paid work hours	883	10.392	17.654
Burden (score = 0-36, 9-16=moderate, 17+=severe)	882	16.184	8.134
Depression (score = 0-15, 6+=probable depression)	880	6.591	1.880
IADL impairments (8 measures, each 0-1)	882	0.881	1.564
ADL impairments (5 measures, each 0-1)	882	0.269	0.730
Hours of informal caregiving	882	112.578	118.065
Size of social network (count of persons)	893	2.267	1.110
% Spouse (yes/no)	892	50.4%	
% Children (yes/no)	893	38.5%	
% 1:30 model	893	45.9%	
Service Use Variables (at 6 months)			
% use adult day care	871	31.3%	
% use companion	871	26.6%	
% use home maker/chore	871	28.7%	
% use personal care	871	34.7%	
% use nursing	871	23.0%	
% nursing home placement	871	11.3%	
% hospital discharge	871	21.0%	

[1] No standard deviation shown when the variable's distribution is represented by a percentage.

Table 2-3: Factor Loadings of Case Management Variables

Variable	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	Factor 6
RN assessment				61		
Crisis assessment			31			
Routine assessment	52					
Care plan development	79					
Care plan revision	61					
Care plan problem resolved		42				
Service provider contact	69					
Ongoing service adjustment	42			45		
Routine monitoring	76					
Change service provider	49					
Quality problem solved	58					
Placement discussed		34				50
Placement assistance offered						55
Discharge planning						35
Referral non demon social service				34	36	
Entitlement assistance				30		
Health service assistance			32			
Referral non demo support group					75	
Referral demo support group				31		
Asst Cg getting to support group				35		
General Cg support		35		49		
Non demo Cg counseling					72	
Disease info to Cg		56			37	
Cg ADL training		56				
Behavior management to Cg		77				
Client mental health		37				
Therapy intervention		42				
Home env modification	35					
Client meds changed		30				
Crisis referral			87			
Obtained crisis services			51			
Contacted public guardian					41	
Contacted APS			81			
Cm medical consult				32		

[1]Variance explained in each variable by factor x 100. Cg= caregiver, Cm=case manager, APS=adult protective service. Values of 30 or more were required to load on a factor. A few items loaded on more than one factor.

Table 2-4: Baseline Caregiver and Client Characteristics Associated with Case Management Factors at Baseline and Six Months[1]

MODEL	Factor 1 Base/6 months	Factor 2 Base/6 months	Factor 3 Base/6 months	Factor 4 Base/6 months	Factor 5 Base/6 months	Factor 6 Base/6 months
Client variables						
Mild/MMSE score		-.41/	-.19/	-.70/	-.40/-.30	
Moderate MMSE			-.14/-.18	-.54/-.45	-.40/-.30	-.40/
Behavioral Problems	-.08/			-.08/.09		-.10/
Left alone safely			. 10/		.37/	
ADL impairments	.11/	-.06/	-.02/	-.08/	-.10/-.05	
Unmet ADL needs		/-.09		-.22/		
Unmet IADL needs		/.13		.10/		
Caregiver variables						
Paid wk hours	-.01/.-03	-				-.01/-.09
Employment affected			-.05/			
Burden		.03/.02		.03/	.01/.02	
Depression	-.19/					.11/.26
IADL impairments	.54/	0.67/		.48/.28		.33/.50
ADL impairments	.56/.70	-0.16/				
Hours informal caregiving	.01/					
Size social network	.37/					.22/.20
Child	-.30/		-.28/		-.03/	
Spouse			-.27/		-.01/-.04	
Length of time caregiving from baseline			.001/			-.30/
1:30 model				-.30/-.30	-.10/	-.30/-.40

[1] Significant ($p<.05$ or less) standardized correlation coefficients for 6 and 12 months respectively. n=893 at baseline and 871 at six months. Variables not significantly related to any factor are not shown in table.

Table 2-5

Case Management Factors Associated with the Likelihood of Service Use
(n=871)

Variable	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	Factor 6
Adult Day Care						
Companion Care	OR=1.53 (p<.001)	OR=.70 (p<.001)	OR=.51 (p<.02)			
Homemaker chore	OR=1.52 (p<.01)		OR=.65 (p<.05)	OR=.76 (p<.02)		OR=.81 (p<.09)
Personal Care	OR=1.34 (p<.01)			OR=1.24 (p<.01)		
Nursing Services	OR=1.30 (p<.002)					
Nursing Home	OR=.59 (p<.02)					
Hospital				OR=.70 (p<.0001)		OR=1.17 (p<.008)

The first row in each cell is the odds ratio derived from a logistic analysis of the likelihood of service use over the client's exposure period in the demonstration. The models control for case manager-to-client ratio, client living arrangements, mental status, medical problems, level of supervision required, a measure of caregiver support, hours of caregiving, and client unmet ADL needs. These variables were retained from a larger list of covariates because they were found to be statistically significant in the full models. p value refers to the statistical significance, results are shown only when p<.05 or smaller.

Chapter 3

Effects of the Demonstration on Caregiver Hours and Task Assistance

by

Cathleen Yordi, DSW[1]
Richard DuNah, MA[1]
Alan Bostrom, MS[1]
Patrick Fox, PhD[1]
Anne Wilkinson, PhD[2]
Robert Newcomer, PhD[1]

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[1]University of California, San Francisco
[2]George Washington University

Abstract

A randomized three year study assessed the effect of expanded community-based services and case management on 5,254 caregivers of dementia clients. Two-stage Hierarchical Linear Models were used for the analysis. Relative to controls, the rate of decline in assistance for Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL) was slower for treatment group caregivers. Unmet needs for the treatment group caregivers decreased by 30 percent within six months and by about 20 percent over 36 months relative to controls. No treatment control group differences were found in assistance by secondary caregivers, assistance by formal service providers, or primary caregiving hours during the study period.

The support network which can augment a primary caregiver's efforts to maintain a person with dementia at home includes both informal caregivers and formal service providers. Primary caregivers of frail elderly people spend, on average, four hours per day in caregiving activities (Stone, Cafferata, & Sangl, 1987). Assistance with the primary caregiving role, provided by other family members or friends, can buffer or mediate the primary caregiver's response to stressful aspects of caregiving (Pearlin, 1990). Services provided by paid non-family service providers, can also reduce the strain of caregiving by offering a respite from this role.

Historically, most of the long term care for functionally impaired elderly has been provided by informal caregivers (Shanas, 1979; Rivlin & Wiener, 1988). The national Long Term Care Informal Caregiver Study found approximately 2.2 million caregivers providing unpaid assistance to 1.6 million non institutionalized frail elderly (Stone, et al. 1987). Soldo and Manton (1985) found extremely disabled elderly living in the community turn to the formal care system only after care needs become more than primary and ancillary caregivers can handle alone.

One of the main barriers to the expansion of in-home and community-based care has been fear on the part of policy makers that paid care will erode the informal care being received by impaired elderly (Congressional Budget Office, 1977; Health Care Financing Administration, 1981). The critical concern is the extent to which families may shift care responsibilities, and the associated costs, to the public sector if expanded in-home and community-based services are available through public funding. One study estimated that over 27 million unpaid days of informal care are provided each week (Liu, Manton & Liu, 1985).

The literature suggests several different ways that the introduction of formal services may impact on informal caregiving (Greene, 1983; Litwak, 1985; Noelker & Bass, 1989). Informal caregiving could be entirely replaced by formal services; the overall level of informal caregiving could be reduced; the level of informal caregiving could be shifted from one type of care to other types of care with which the caregiver is more comfortable providing or better able to provide; or informal care may be extended for longer periods of time, possibly increasing the total effort over time even when less care is provided in the short run.

Research from earlier long term care demonstrations indicates that a major shift from unpaid to paid care is unlikely. A re-examination of all the home and community-based long-term care studies conducted between 1960 and 1988 (Hanley, Weiner & Harris, 1991), found that of 53 evaluations that studied the impact of formal services on the amount of informal care provided, 45 showed no significant change in informal care, seven showed a statistically significant increase in informal care, and four found a statistically significant decrease in informal care. When reductions in caregiving were found, they reflected a redirection of family help rather than a reduction in their overall effort.

The general consensus among studies examining the substitution of formal care for the provision of informal care has been that the effect is small or statistically non-significant, see for example, the California, Chicago, and Minnesota Home Care Programs (Smith-Barusch & Miller (1985), the Channeling Demonstration (Christianson, 1986), the Hospital Program Community Care Project in the Chicago area (Edelman & Hughes, 1990), and the Minnesota Pre-Admissions Screening/Alternative Care Grants Program (Moscovice, Davidson & McCaffry, 1988).

Studies focusing on persons with dementia have found about half of the primary informal caregivers provide care with no outside assistance (Gwyther, 1989). Further, even when formal services were offered at low cost, empirical findings indicate caregivers of persons with dementia consistently underutilized the formal services available (Biegel, Bass, Schulz & Morycz, 1993; Parris-Stephens, 1993). Until now, no experimental studies have examined the impact of formal care on the provision of informal care for persons with dementia, or of the affect of this assistance and caregivers themselves.

The Intervention

Funded by the Health Care Financing Administration, the Medicare Alzheimer's Disease Demonstration and Evaluation was designed to address policy issues related to the cost, benefits and effectiveness of expanded community based services for persons with dementia and their caregivers. Demonstration goals included: developing a network of in-home community-based services to address the medical, mental health, and social support needs of persons with

Alzheimer's disease and related disorders and their caregivers; providing education and support services to caregivers to minimize stress associated with caregiving and to enhance caregiving skills; creating opportunities for demented persons to be cared for in protective home environments but supporting the use of the most appropriate level of care whether in an institutional or community setting; and providing in-home and community-based services. Criteria for enrollment in the demonstration were that all eligible applicants have a physician certified diagnosis of an irreversible dementia, be enrolled in or be eligible for both Parts A and B of the Medicare program, have service needs due to cognitive or functional impairment, and reside in the demonstration's catchment area.

Case management was the foundation of the demonstration. It was viewed as the key service component for both the demented client and the caregiver. Case managers assessed client and caregiver needs; assisted the caregiver in determining the most appropriate mix of services to meet the client's needs; activated a plan of care with home and community-based services largely reimbursed under the Medicare demonstration; and monitored the quality of care provided. Two intervention models were implemented. These differed on the case manager-to-client ratio and the per-month service expenditure cap for each client. The differences in case management intensity and service expenditure caps were designed to test the intervention at two different levels of funding. Model A sites operated with a target case manager to client ratio of 1:100 and had a monthly community service reimbursement limit or cap from $290-489 per month per client. Model B sites operated with a target case manager to client ratio of 1:30 and had a higher reimbursement limit of from $430-699 per month per client. The per month reimbursement caps in each model varied by site over time due to regional cost variations and inflation adjustments. Acute care and other skilled care services continued to be reimbursed as part of the regular Medicare benefit. Services reimbursed under the service cap included:

- adult day care
- skilled nursing and rehabilitation nursing
- therapies (i.e., speech, occupational, physical)
- home health aide;
- homemaker/personal care
- housekeeping

inimum of two data points per study participant in order to estimate the slope of a caregiver's ctivity over time. For this reason, 189 clients were excluded because they had no informal aregiver at baseline. An additional 2,695 were excluded from the analysis because they had only ne assessment while they lived in the community. Data collected after a client had a change in rimary caregiver or was institutionalized were not considered in assessing caregiver outcomes.

The caregiver support network analysis is, therefore, based on 5,254 clients who received baseline assessment and up to five reassessments over the 36 month study period. This roduced a total of 19,929 observations. This subset of clients are used for all descriptive atistics. The sample sizes for the five outcome measures vary slightly due to missing data (less an three percent overall). The baseline sample size by site and observations by reassessment eriod are both shown in Table 3-1. At the end of the three year study period, 34 percent of the itial sample was still residing in the community and received a 36 month, final reassessment. ttrition from the study has been given detailed attention in a separate analysis examining nursing ome placement and mortality rates. This work has shown no differential attrition from either eatment or control group (see Chapter 6 in this report). Statistical power for the analysis is high, ith an ability to detect differences of less than 5 percent between treatment versus control omparisons and comparisons involving each model separately (alpha=.05, Power=.99). For omparisons involving site level subgroups the effect broadens to 10 percent (alpha=.05 one-iled, Power=.80) for all but the smallest enrollment site (i.e., West Virginia). These are onservative power estimates because they are based only on the count of the baseline cases for hom at least two data points were available. At least two data points are needed to estimate the ope. If all observations are included in the slope estimate, the effective sample increases from ,254 cases to 19,929. With this sample size, power approaches .80 or greater in seven of the ight sites (alpha=.05), with an ability to detect a differences between groups of about 5 percent. ower in West Virginia at this effect is .65. The means test comparisons (Table 3-3) use cases, the LM comparisons (Table 3-4) are based on observations.

Table 3-1 About Here

Model Specification

Based on a review of the informal caregiver literature, a set of client and caregiver characteristics were selected as control variables for the analyses of five caregiver support network outcome measures. The control variables in the model included: (a) group assignment and model, (b) client characteristics, and (c) caregiver characteristics. Client and caregiver data were obtained from baseline assessment interviews conducted with the client's primary caregiver. All assessment data is self reported by the primary caregiver. Client and caregiver functional status was measured by a version of the Katz activities of daily living (ADL) scale (Katz & Akpom, 1976), Lawton and Brody's instrumental activities of daily living (IADL) scale (Lawton & Brody, 1969). Client behavioral problems were assessed using an adaptation of the index developed by Zarit, Todd, and Zarit (1986). Client cognitive status was measured by the mini-mental status examination (MMSE) (Folstein, Folstein & McHugh, 1975). These scales and indices are widely used because of their reliability and predictive validity. The specific items and scale ranges are shown in Figure 3-1.

Insert Figure 3-1 About Here

The five outcome measures are described below.

Primary Caregiver Hours Per Week. The primary caregiver's level of involvement was measured as the average number of hours per week spent helping and assisting the client with tasks he/she was unable to perform alone. At baseline, primary caregivers were spending on average 86.2 hours per week (12.3 hours per day) providing care.

Primary Caregiver ADL/IADL Tasks. Support provided by the primary caregiver was measured by summing the number of ADL tasks (eating, transferring, dressing, bathing, toileting) and IADL tasks (meal preparation, shopping, routine housework, managing money, laundry, medications, telephoning, and heavy chores) for which the primary caregiver was the principal provider (i.e., the person who helped most with the task). At baseline, primary caregivers were the principal providers of care on an average of 8.1 of the 13 possible ADL/IADL tasks.

ıe between group variance (in this analysis, among sites). This leads to more efficient estimates ıd higher statistical power.[2]

Bryk and Raudenbush (1987) showed how this modeling framework can supply estimates f the mean trajectory, of individual variation around the means, of the reliability of measures of ıange, of the correlation between true status at any time and true rate of change, and of correlates f change. HLMs are elsewhere described as "multilevel models" (Goldstein, 1995) or "random oefficient models" (Gibbons, Hedeker, Waternaux, & Davis , 1988; Longford, 1993). For a full xplanation of HLM refer to Hierarchical Linear Model - Applications and Data Analysis Methods Bryk and Raudenbush, 1992).

The control group is the reference group for all of the HLM treatment/control comparisons resented in Table 3-4. A negative difference reported in the table means the treatment group ıtercept (shown as the baseline difference) or slope is lower for the treatment group compared to ıe control group. The slope differences presented in Table 3-4 are given in outcome measure nits per month. The difference between groups at 36 months can be computed by multiplying the ope difference per month by 36 and adding the result to the intercept difference.

Two other variables were included in all of the HLM analyses: number of months in the udy (ranging from 6 to 36) and cohort (which classified each client into four groups of equal size ased on date of entry to the study. These are intended to adjust for unmeasured differences in aregiver outcomes that might be associated with attrition or program entry period dimensions.

Treatment site and model (A vs. B) were confounded given that each site was assigned to e either a Model A or a Model B site and subjects were not randomized to site (the sites were in ifferent states). This confounding prevented testing the Model hypothesis in a single equation ontrolling for site effects. To eliminate this problem, separate HLM models were run for Model

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HLM can have more than two levels, allowing for multiple nested subgroups. In this demonstration a hierarchical ıbgroup beyond caregiver (level 1) and site (level 2) conceptually might have included intervention Model (A & B). LM procedures, however, do not produce stable results if the sample size at a level is too small. Eight sites is at e margin of an acceptable size. Recognizing this limitation we tested demonstration effects using separate HLM odels for Model A and Model B sites. Treatment status (another conceptual analytical level) was tested directly in l models as a main effect and as a interaction term with selected covariates.

in caregiving hours between the treatment and the control group was also not significant (slope = -.03).

Table 3-4 about here

Model Effect: To test for a difference in treatment effect between models while controlling for site differences, the fully specified HLM model (including site dummy variables) was run separately for Model A and Model B caregivers. There was no significant treatment effect in either model. This is consistent with the hypothesized lack of impact on primary caregiving hours over time.

Site Differences: To test whether the treatment effect varied for the eight demonstration sites, terms representing the interaction between site and treatment group were entered into the HLM model. None of the interactions were significant, indicating no treatment effect on primary caregiving hours in any of the demonstration states.

Subgroup Analyses: To determine whether the intervention effect on primary caregiving hours varied by client or caregiver characteristics, interactions between the treatment group assignment and client age, gender, ethnicity, functional dependency, behavioral problems, prior hospitalization, and Medicaid eligibility were examined. Interactions between treatment group assignment and caregiver income, co-residency, functional limitations, and health status were also examined. None of the interactions were significant indicating there were no differences in primary caregiving hours between the treatment and control groups for any of the subgroups examined.

Primary Caregiver ADL/IADL Tasks

At the outset of the study, primary caregivers were, on average, the principal providers of care on eight of the possible 13 ADL/IADL tasks. As shown in the second grouping in Table 4, the number of tasks for which the primary caregiver was the principal provider declined over time by approximately one-half of a task (mean slope = -.014 per month x 36 months). The rate of decline was slower for the treatment group than the control group (.009 of a task per month or .4 of a task at the end of three years, $p < .05$). While the difference is significant, the .4 task difference is quite small relative to the mean number of tasks performed by primary caregivers at

36 months (7.5 tasks). No difference in treatment effect was found between models, demonstration sites, or client and caregiver subgroups using analyses similar to those discussed previously.

Secondary Caregiver Assistance with ADL/IADL Tasks

Secondary caregivers on average were providing assistance to clients with three ADL/IADL tasks (average intercept = 2.9) at baseline. See the third grouping of results in Table 3-4. There was no significant difference between the treatment and control group at the baseline intercept or the slope (slope = -.04 per month). The findings do not support the hypothesis that assistance provided by secondary caregivers in the treatment group would increase relative to the control group. No difference in treatment effect was found between models, demonstration sites, or client and caregiver subgroups. This finding was unanticipated as one of the case manager's roles was to maximize a client's caregiving network, including bringing in secondary caregiver support if primary caregivers were in poor health or overburdened.

Formal Provider Assistance with ADL/IADL Tasks

Clients were receiving assistance from formal service providers with an average of three ADL/IADL tasks (average intercept = 2.6) at the outset of the study. See the fourth grouping of results in Table 3-4. Assistance from formal providers doubled over time (slope = .08), an increase of 2.9 tasks by 36 months. The increase was slightly faster for the treatment group, but the difference was not significant (slope = .006). This finding does not support the hypothesis that predicted increased assistance from formal providers for the treatment group compared to the control group. The lack of a treatment effect is unexpected given the additional community-based services made available under demonstration funding to the treatment group clients. No difference in treatment effect was found between models, demonstration sites, or client and caregiver subgroups.

Unmet Need for Assistance with ADL/IADL Tasks[5]

Treatment Effect: Primary caregivers reported relatively few unmet needs for assistance with ADL and IADL tasks, yet as seen in the final group of results in Table 3-4, there is a notable treatment effect in the HLM analysis as shown by the slope term. At 36 months, unmet needs for the control group had decreased from 1.8 to 1.6, a 12 percent decline, while the treatment group level of unmet need declined to 1.3 at 36 months, a reduction of about 30 percent ($p < .001$) relative to baseline and 20 percent relative to the control group at 36 months. These numbers vary slightly from the unadjusted means reported in Table 3-3. This disparity is, in part, an artifact of the HLM's attempt to fit the data to a linear function, and in part reflective of the multivariate adjustments of the HLM. Differences can occur at the intercept either due to baseline differences in the groups (which was not the situation here due to successful randomization), or because of a non-linear response over time for one or both groups. There is some evidence of a non-linear response in Table 3-3. Unmet needs for ADL/IADL task assistance dropped rapidly for the treatment group during the first six months after enrollment. These rates then remained relatively flat over the remainder of the study period. Among controls, reported unmet need decreased slowly after baseline, but with minor rises and falls, although not reaching the levels of unmet need reported during their application to the program. Unlike primary caregiver hours (in which it appears that both samples of applicants may have reported higher baseline levels of need, perhaps with the expectation that this would influence their selection into the demonstration treatment group) the relative constancy of unmet need in the controls seems to argue against inflated reporting at time of application. However, even assuming that the prevailing level of unmet need may be closer to 1.6 tasks shown through the balance of 36 months rather than the 1.8 tasks reported at baseline, the simple means comparisons in Table 3-3 continue to show a significant treatment effect, as do the multivariate HLM comparisons in Table 3-4.

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[5] The goodness of fit of an HLM model is tested by iteratively tracking reductions in the -2log likelihood (iterations terminate when the likelihood fails to change). Statistical significance is tested using a chi-square. There is no convenient sample size independent metric like r^2 to interpret the amount of variance explained. All HLM models are statistically significant $p<.0001$.

To further test the sensitivity of the HLM findings to the assumption of a linear change, the fully specified HLM models were run for 12 and 24 month reassessment intervals separately (not shown here). As the time lengthened the estimated slope differences weakened (going from -.0391 at year one to -.0213 and -.0123 in years two and three respectively). All these results were statistically significant ($p<.001$ or lower). Thus the 36-month HLM analysis may underestimate the true treatment effect.

Model Effect: To test for a difference in treatment effect between models, the fully specified HLM model was run first for Model A and then for Model B. The magnitude of the intercept difference between the treatment and control group was approximately the same for Model A and B. The slope, however, was almost three times steeper for Model A than for Model B (-.019 versus -.007, $p < .05$). This finding is inconsistent with our hypotheses given that Model B clients would be greater than those of Model A given the presence of more resources.

Other Impacts: The treatment effect did not vary for the eight demonstration sites or for any of the client or caregiver subgroups examined.

Type of ADL/IADL Assistance Provided by Primary, Secondary and Formal Providers

Recognizing that all functional tasks may not be of equal importance or complexity (see for example Finch, Kane & Philp, 1995) and that aggregations of needs combining multiple data items (see for example Manton, Newcomer, Vertrees, Lowrimore & Harrington, 1994) are emerging as methods for classifying the functional capability, the analysis examined the specific ADL and IADL assistance needs in addition to summed need scores. In particular, the concern was to isolate differences between treatment and control groups on specific task need, and to elucidated which tasks were most sensitive in identifying the reduction in unmet needs.

To determine if there were differences between groups in the type of assistance received or if there was a substitution or shift in the types of care provided over time, primary caregiver, secondary caregiver and formal provider assistance with specific types of ADL and IADL tasks were examined at baseline and 24 months. The data in Table 3-5 show similar patterns of caregiver assistance for both the treatment and control group. Over time, primary caregivers in

both groups decreased assistance with a number of IADL tasks, while increasing assistance with the majority of the ADL tasks. The relatively small amount of assistance being provided to primary caregivers by secondary caregivers at baseline decreased even further over time on most of the ADL and IADL tasks for both the treatment and control group. Assistance with ADL and IADL tasks by formal providers increased over time on almost every task, for both groups.

Table 3-5 About Here

These data indicate that over time, presumably as the client's needs increase, formal providers are utilized by some of the caregivers to assist with all types of tasks. There remains, however, a major difference between the large proportion of clients in both groups who are receiving help from a primary caregiver and the small proportion of clients receiving help from a formal provider. Primary caregivers are getting some relief from formal providers mainly with tasks performed by homemaker chore/personal care workers such as meal preparation, shopping, housework, and laundry, dressing and bathing. On the other hand, formal providers are not providing substantial relief with two ADL tasks--transferring and toileting. These findings suggest that the demonstration service coverage produced a task-related pattern of service use approximately equal to that of those purchasing services out of pocket.

To explore more fully whether there were differences in how this assistance was targeted on unmet needs, Table 3-6 shows the proportion of cases at baseline and at the 24 month reassessment interval with specific unmet task needs. This sample only includes those individuals who had unmet needs at baseline and/or at 24 months.

The treatment and control groups had substantively different patterns of change in unmet needs. For the treatment group, there were reductions in unmet needs at 24 months on all of the IADL tasks and two of the ADL tasks. For the control group, there were significant reductions in unmet needs on only four of the eight IADL tasks; but more importantly, there were significant increases in unmet needs on four of the five ADL tasks. Further, control group clients had a larger proportion of clients with unmet needs on every ADL and IADL tasks. In other words, the demonstration seems to have achieved a better match of services with client expressed task needs

than were achieved by the control groups, even though overall service use and task assistance levels were similar.

Insert Table 3-6 About Here

SUMMARY and DISCUSSION

The results support two of the five previously stated hypotheses.

1. While there was an overall decline in primary caregiving hours for both groups, there was no difference in the rate of decline between the treatment and control groups. These findings support other research which shows no significant change in informal care when formal services are available.

2. There was a small decline in the number of ADL/IADL tasks provided by the primary caregivers over time. Contrary to the hypothesis, which predicted no difference between groups, there was an unanticipated outcome. The rate of decline in primary caregiving tasks was significantly slower for the treatment group than the control group, although the effect size was small ($p < .05$).

3. The level of secondary caregiver assistance was low at baseline and declined for both the treatment and control group over time. This finding was unexpected, as one of the objectives of the case management intervention was to maximize the client's caregiving network by encouraging other family members and friends to assist with caregiving if the primary caregiver was in poor health and/or experiencing stress and burden as a result of caregiving.

4. Consistent with the hypothesized demonstration effect, the number of unmet needs decreased significantly faster for the treatment group than the control group (30% reduction at 36 months for the treatment group versus a 12% reduction at 36 months for the control group). This difference in the reduction of unmet needs occurred even though caregiving by secondary informal caregivers and formal service providers was equivalent for the treatment and control groups.

5. Assistance from formal providers with ADL/IADL tasks doubled over the 36 month study period. By the end of the study, the level of support from formal providers approached the level of support provided by primary caregivers (5.2 versus 7.6 ADL/IADL tasks). Although the rate of increase in formal support was equal for the treatment and control group, there is some evidence that the treatment group received a better match between the IADL/ADL task assistance needed and the services received.

The two models of care (Model A: low resource and Model B: high resource) were implemented to test the demonstration at different levels of funding. The lack of a differential impact between the two models on three of the outcome measures coupled with greater impacts in Model A sites than Model B sites on the other two outcomes (unmet needs and primary caregiver as provider of ADL/IADL tasks), suggests that more intensive case management (1:30 ratio vs. 1:100) and larger monthly expenditures ($699 vs. $430) for community-based services were not sufficient for differentiating caregiver support outcomes.

Formal services reimbursed by the demonstration were used as an adjunct or supplementation to primary caregiver efforts. While there were small decreases in primary caregiving on specific IADL tasks, caregiving was maintained or increased on four of the five ADL tasks. On average primary caregiver assistance with ADL/IADL tasks declined significantly less over time for the treatment group than the control group.

The equivalent use of assistance from formal providers by both groups suggests two conclusions. First, it indicates case managers may have made access to these services easier for the treatment group caregivers, but many control group caregivers were able to find and pay for these services on their own. Second, differences between the two groups in how formal provider assistance was used may be due, in part, to the unwillingness of some primary caregivers to use formal services for various tasks without encouragement from case managers (or other sources not measured here).

A logical extension of these findings is research into the relationship between unmet needs and caregiver burden, and whether reducing unmet needs helps caregivers retain their family

members in the community. Such demonstrable successes are the "bankable" program benefits hoped for by policy makers and the designers of the Medicare Alzheimer's Disease Demonstration.

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Figure 3-1

Caregiver Support Network Outcomes: Model Specification

Independent Variables

Site

Experimental Variables
Group (1 = Treatment Group)
Model (1 = Model B:High Resource)

Client Characteristics
Age (20 - 103 years)
Gender (1 = Male)
Ethnicity (1 = Minority)
Functional Dependency Scale (-2.6 to +1.8)
Mini-Mental Status Examination (0-30)
Behavioral Problems Scale (0 - 19)
Hospitalized in prior 6 months (1 = Yes)
Medicaid Eligible (1 = Yes)

Caregiver Characteristics
Age (16 - 100 years)
Relationship to Client
- Spouse (1 = Yes)
- Unmarried child (1 = Yes)
- Married child (1 = Yes)
- Other (omitted)

Income (0 - 11)
Lives with Client (1 = Yes)
Functional Limitations Index (0 - 13)
Health Status (1 - 4)
Secondary Caregiver Assistance with ADL/IADL Tasks (0 - 13 tasks)
Formal Provider Assistance with ADL/IADL Tasks (0 - 13 tasks)

Outcome Variables

Caregiver Support Network
Primary Caregiver Hours Per Week (0 - 168 hours)
Primary Caregiver ADL/IADL Tasks (0 - 13 tasks)
Secondary Caregiver Assistance w/ ADL/IADL Tasks (0 - 13 tasks)
Formal Provider Assistance with ADL/IADL Tasks (0 - 13 tasks)
Unmet Need for Assistance with ADL/IADL Tasks (0 - 13 tasks)

Table 3-1

The Study Sample: Caregiver Support Network Analysis

Site	Control	Treatment	Total
Florida	384	398	782
Illinois	314	313	627
Minnesota	424	464	888
New York	318	313	631
Ohio	254	311	565
Oregon	333	360	693
Tennessee	318	338	656
West Virginia	202	210	412
Total	2,547	2,707	5,254

Assessment Interval	Original Sample*	Expanded Sample**	Total Sample
Baseline	4,422	832	5,254
6 Months	4,321	-	4,321
12 Months	3,217	-	3,217
18 Months	2,560	30	2,590
24 Months	1,963	739	2,702
30 Months	54	24	78
36 Months	1,259	508	1,767
Total Observations	17,796	2,133	19,929

* The the original sample was reassessed at 6, 12, 18, 24 and 36 month intervals. The 30 month reassessments were obtained retrospectively for those who died between 27 and 33 months.

**The expanded sample was interviewed at baseline and then at the 24 and 36 month intervals. The 18 month reassessments were obtained retrospectively for those who died between 15 and 21 months. The 30 month reassessments were obtained retrospectively for those who died between 27 and 33 months.

Table 3-2

Baseline Variables Used as Controls for Caregiver Support Network Outcomes[1]

Baseline Predictors	Treatment Group (n=2707) Mean	SD	%	Control Group (n=2547) Mean	SD	%
Client Characteristics						
Age	78.3	8.0		78.3	8.4	
Gender (Male)			38.0			40.6
Ethnicity (Minority)			12.6			13.5
Functional Dependency[2]	(0.0)	1.0		(0.1)	1.0	
ADL Impairment[3]	3.7	3.2		3.5	3.2	
IADL Impairment[4]	12.7	3.6		12.6	3.7	
MMSE[5]	14.8	8.6		15.2	8.6	
Behavioral Problems[6]	8.2	3.8		8.2	3.8	
Hospitalized prior 6 mo.			21.2			20.5
Medicaid Eligible			6.4			6.6
Caregiver Characteristics						
Age	63.0		14.2	62.5	14.4	
Relationship						
Spouse			48.6			48.6
Married Child			27.3			27.4
Unmarried Child			15.7			14.4
Other			8.3			9.5
Lives with Client			74.0			73.1
Income < $15,000			45.0			45.4
Caregiver Functional Limitations[7]	1.0	2.0		1.0	1.9	
Caregiver Health Poor/Fair			21.9			21.7
Secondary Caregiver Assistance[8]	3.2	4.4		3.3	4.5	
Formal Provider Assistance[9]	2.5	3.9		2.5	3.7	

[1]There were no significant differences ($p < .05$) between the treatment and control groups on any of the baseline measures.

[2]The measure is a standardized score (including ADL, IADL and mental impairment) with a mean of 0 and a standard deviation of 1. Scores ranged from -2.6 to +1.8. Higher scores indicate a higher level of functional dependency.

[3]Scores can range from 0 to 10. Higher scores indicate greater ADL impairment.

[4]Scores can range from 0 to 16. Higher scores indicate greater IADL impairment.

[5]Scores can range from 0 to 30. Lower scores indicate greater cognitive imparirment.

[6]Scores can range from 0 to 19. Higher scores indicate a greater number of behavior problems.

[7]Scores can range from 0 to 13. Higher scores indicate greater functional limitations.

[8]Scores can range from 0 to 39. Higher scores indicate greater assistance with ADL/IADL tasks by secondary caregivers.

[9]Scores can range from 0 to 39. Higher scores indicate greater assistance with ADL/IADL tasks from formal providers.

Table 3-3
Mean Scores on the Caregiver Support Network Outcomes At Each Reassessment Interval[1]

Outcome Measure	Treatment Group n	Treatment Group Mean	Treatment Group Standard Deviation	Control Group n	Control Group Mean	Control Group Standard Deviation
Primary Caregiving Hours						
Baseline	2707	87.3	58.3	2547	85.1	59.0
6 Months	2221	66.9	50.9	2100	63.2 *	51.7
12 Months	1658	67.8	52.7	1559	66.2	54.6
18 Months	1365	63.4	53.5	1225	64.0	55.9
24 Months	1430	64.1	53.4	1324	65.0	56.4
36 Months	911	69.9	58.2	856	67.8	58.5
Primary Caregiver is Principal Provider of ADL/IADL Tasks[2]						
Baseline	2707	8.2	3.6	2547	8 *	3.6
6 Months	2266	7.9	3.8	2142	7.7 *	4.0
12 Months	1724	7.9	2.6	1621	7.7	2.9
18 Months	1454	7.9	4.2	1324	7.4 **	4.3
24 Months	1540	7.9	4.3	1380	7.5 *	4.4
36 Months	987	8.0	4.5	922	7.8	4.5
Secondary Caregivers Assist with ADL/IADL Tasks[3]						
Baseline	2707	3.3	4.4	2547	3.2	4.6
6 Months	2266	2.2	3.7	2142	2.3	3.9
12 Months	1724	2.1	3.5	1621	2.2	3.8
18 Months	1454	1.9	3.5	1324	2.0	3.5
24 Months	1540	1.8	3.5	1380	2.2 *	4.0
36 Months	987	2.0	3.9	922	2.2	4.0
Formal Providers Assist with ADL/IADL Tasks[4]						
Baseline	2707	2.5	3.9	2547	2.5	3.7
6 Months	2266	3.4	4.1	2142	3 **	4.5
12 Months	1724	3.7	4.4	1621	3.5	4.8
18 Months	1454	4.1	4.5	1324	3.8	5.0
24 Months	1540	4.6	5.0	1380	4.3	5.3
36 Months	987	5.4	5.5	922	4.7 *	5.3
Unmet Needs for Assistance with ADL/IADL Tasks[5]						
Baseline	2707	1.8	2.2	2547	1.8	2.1
6 Months	2266	1.2	2.2	2143	1.8 ***	2.8
12 Months	1724	1.2	2.9	1621	1.5 ***	3.2
18 Months	1454	1.1	2.8	1324	1.6 ***	3.2
24 Months	1540	1.0	2.8	1380	1.7 ***	3.4
36 Months	987	1.2	3.1	922	1.6 ***	3.4

[1]Mean scores are unadjusted.

[2]Scores can range from 0 to 13. Higher scores indicate caregiver is the principal provider of care on more ADL/IADl tasks.

[3]Scores can range from 0 to 39. Higher scores indicate greater assistance with ADL/IADL tasks by secondary caregivers.

[4]Scores can range from 0 to 39. Higher scores indicate greater assistance with ADL/IADL tasks from formal providers.

[5]Scores can range from 0 to 13. Higher scores indicate greater unmet needs.

* $p < .05$; ** $p < .01$; *** $p < .001$. T-test were used to determine significant differences between treatment/control groups.

Table 3-4
Summary of HLM Analyses of Caregiver Network Outcomes[1]

OUTCOME MEASURE	Baseline[2] Mean or Difference	Slope[3]	36 Month Mean or Difference[4]
Primary Caregiving Hours Per			
Sample Mean	80.000	(0.520)	61.280
Sample Treatment/Control Difference	0.750	(0.030)	(0.330)
Model A Treatment/Control Difference	1.200	(0.020)	0.480
Model B Treatment/Control Difference	0.550	(0.060)	(1.610)
Primary Caregiver is Principal Provider of ADL/IADL Tasks			
Sample Mean	8.000	(0.014)	7.490
Sample Treatment/Control Difference	0.065	0.009 *	0.400
Model A Treatment/Control Difference	0.063	0.013 *	0.530
Model B Treatment/Control Difference	0.075	0.005	0.250
Secondary Caregiver Assistance with ADL/IADL Tasks			
Sample Mean	2.900	(0.040)	1.460
Sample Treatment/Control Difference	(0.150)	(0.000)	(0.160)
Model A Treatment/Control Difference	(0.140)	(0.004)	(0.270)
Model B Treatment/Control Difference	(0.170)	(0.000)	(0.180)
Formal Provider Assistance with ADL/IADL Tasks			
Sample Mean	2.600	0.080	5.500
Sample Treatment/Control Difference	0.050	0.006	0.280
Model A Treatment/Control Difference	0.060	0.001	0.100
Model B Treatment/Control Difference	0.070	0.013	0.540
Unmet Need for Assistance with ADL/IADL Tasks			
Sample Mean	1.800	(0.013)	1.600
Sample Treatment/Control Difference	(0.270) **	(0.012) ***	(0.700)
Model A Treatment/Control Difference	(0.330) ** (0.019	**	(1.000)
Model B Treatment/Control Difference	(0.300) **	(0.007)	(0.550)

[1]The control group is the reference group for all comparisons

[2]If the difference is negative, then the treatment group is lower than the control group

[3]In units per month. If difference is negative, then the treatment group slope is less than the control group slope.

[4]Total difference between the treatment and control group at 36 months (baseline difference + 36 months x slope)

*p < .05, ** p < .01, *** p < .001

Table 3-5
Type of ADL/IADL Assistance Provided by Primary Caregivers, Secondary Caregivers and Formal Providers at Baseline and 24 Months[1]

Caregiver and Type of Care	Treatment Group (n=2,707) Baseline	Treatment Group (n=2,707) 24 Months	% Difference	Control Group (n=2,547) Baseline	Control Group (n=2,547) 24 Months	% Difference
PRIMARY CAREGIVERS						
ADL Assistance (%)						
Eating	40.3	47.3	7.0 ***	36.8	43.2	6.4 **
Dressing	54.7	53.0	-1.7	51.0	49.1	-1.9
Bathing	52.3	52.5	0.2	48.8	49.2	0.6
Transferring	27.1	32.1	5.0 **	24.6	29.3	4.7 **
Toileting[2]	34.4	43.7	9.3 ***	32.6	38.1	5.5 **
IADL Assistance (%)						
Meal Preparation	77.8	70.3	-7.5 ***	75.6	67.7	-7.9 ***
Shopping	84.9	78.2	6.7 ***	81.1	74.7	-6.4 ***
Housework	71.4	65.3	6.1 ***	68.5	63.2	-5.3 **
Laundry	71.8	68.5	-3.2	70.9	67.0	-2.9 *
Medications[2]	77.0	72.1	5.1 **	76.9	68.3	-8.6 ***
Money Management[2]	86.2	88.6	2.4 *	84.5	85.1	0.6
Telephoning	71.7	71.0	-0.7	69.4	69.2	-0.2
Heavy Chores	53.7	51.4	-2.3	49.2	50.1	0.9
SECONDARY CAREGIVERS						
ADL Assistance (%)						
Eating	0.9	1.5	0.6	0.7	1.5	0.8
Dressing	2.6	2.2	-0.4	2.3	2.2	-0.1
Bathing	3.3	2.8	-0.5	4.3	3.2	-1.1
Transferring	1.0	0.8	-0.2	0.7	1.2	0.5
Toileting[2]	1.2	1.5	0.7	0.6	1.2	0.6
IADL Assistance (%)						
Meal Preparation	4.4	3.2	-1.2	4.1	3.5	-0.6
Shopping	6.0	5.1	-0.9	8.3	6.2	-2.1
Housework	4.5	2.9	-2.5 *	4.6	5.3	0.7
Laundry	6.5	4.6	-1.9 *	6.2	4.3	-1.9
Medications[2]	4.0	2.9	-1.1	4.0	3.3	-0.7
Money Management[2]	9.9	6.8	-3.1 **	11.0	8.6	-2.4 *
Telephoning	2.8	1.9	-0.9	2.5	2.2	-0.3
Heavy Chores	16.7	13.5	-3.2 *	18.2	13.6	-4.6 **
FORMAL PROVIDERS						
ADL Assistance (%)						
Eating	3.5	11.0	7.5 ***	4.3	11.2	6.9 ***
Dressing	8.0	19.5	11.5 ***	8.2	20.0	11.8 ***
Bathing	14.1	27.0	12.9 ***	12.2	25.9	13.7 ***
Transferring	2.4	7.6	5.2 ***	2.5	8.2	5.7 ***
Toileting[2]	4.1	13.0	8.9 ***	4.3	13.5	9.2 ***
IADL Assistance (%)						
Meal Preparation	10.8	22.4	11.6 ***	11.8	23.5	11.7 ***
Shopping	4.3	14.4	10.1 ***	4.2	15.3	11.1 ***
Housework	14.5	28.9	14.4 ***	14.5	26.6	12.1 ***
Laundry	10.1	23.2	13.1 ***	11.2	22.2	11 ***
Medications[2]	7.3	17.1	9.8 ***	7.6	18.9	11.3 ***
Money Management[2]	1.1	1.8	0.8	1.1	2.2	1.1 *
Telephoning	3.7	12.7	9.0 ***	3.6	14.5	10.9 ***
Heavy Chores	25.7	32.0	6.3 ***	28.4	32.2	3.9 *

[1] Unadjusted scores. Only those caregivers with a 24-month reassessment were included in this analysis.

[2] $p < .05$ difference between the treatment and control at 24 months using chi-square test of significance.

* $p < .05$. ** $p < .01$; *** $p < .001$ difference between the percentage of clients receiving assistance at baseline and 24 months by group (treatment, control). Chi-square tests were used to determine significant differences between types of assistance at baseline and 24 months within each group as well as differences between the treatment and control group at 24 months.

Abstract

y *Question.* Did the Medicare Alzheimer's Disease Demonstration with its case management community service waivers affect the use of community-based long term care services among le with dementia and their primary caregivers?

Sources. Baseline and periodic caregiver interviews. Measures include client and caregiver outes and self-reported service use.

y *Design.* The demonstration randomly assigned voluntary applicants into treatment and rol groups. Treatment group cases were eligible for case management, and up to $699 per th in community care benefits. The actual monthly entitlement varied among the eight onstration communities due to regional cost and inflation adjustments over time. Analyses are he year after enrollment.

Collection. Analyses are of cases surviving six months or more in the community after llment (n=5,209). Cases received baseline and semi-annual assessments.

cipal Findings. The intervention of case management and community service reimbursement a strong, consistent, and positive impact on the likelihood of using home care (including emaker/chore services, personal care services, companion services) and adult day care. tment group clients were at least twice as likely as control group clients to be using any of the community-based services. A similar, but less pervasive effect was achieved with caregiver ing and support group participation. Reimbursement provided by the demonstration's licare waiver was generally not sufficient to exceed the level of control group service acquired ugh private payment.

clusions. Reimbursement levels within the demonstration may have enabled more individuals rchase some services, but they were not sufficient to increase the average level of use over e in the control group. There were no consistent differences between demonstration models in ice use likelihood or average use among users.

Words. Dementia, case management, home care, adult day care service use.

Prior studies of people with dementia have found that they "under utilize" formal care (cf., Bass, Looman & Ehrlich, 1992; Biegel, Bass, Schulz, & Morycz, 1993; Caserta, Lund, Wright, & Redburn, 1987; Webber, Fox & Burnette, 1994). Among the explanations for this is a general unwillingness of caregivers to seek formal assistance. This reticence is said to arise, in part, because of the presumed stigma associated with dementia, the hassle-factors experienced when bringing providers into the home, and the unavailability of providers that are willing and able to accommodate people with dementia (Ory, Williams, Emr, et al., 1985). Physical activity, meals programs, and other services provided in group settings have a tendency to segregate people with dementia from other participants. Another service supply problem was that homemaker/chore and companion services were limited in quantity and in the availability of staff experienced in working with a demented population (Hooymam, Gonyea, & Montgomery, 1985).

Contributing to these service supply issues is limited insurance coverage for community-based services. Even in public programs such as Medicaid, degenerative cognitive function does not trigger financial assistance unless it is conjoint with physical disability. Even then disability levels may have to qualify for nursing home placement.

In 1989, the Health Care Financing Administration implemented the Medicare Alzheimer's Disease Demonstration and Evaluation (MADDE) program. This was designed to address some of the presumed barriers to community care services: identifying a network of "dementia friendly" community-based services, working with them to develop staff trained in the care of those with dementia, counseling caregivers in the selection of services, providing financial assistance for community care, and monitoring care quality.

This paper reports on whether MADDE was able increase community-based service use among its participants. Other analyses have examined whether the demonstration affected informal caregiver time and the levels of unmet need (see Chapter 3 of this report). Other Chapters in this report examine the caregiver burden and depression, and client nursing home placement among those in the demonstration.

The Medicare Alzheimer's Disease Demonstration

Enrollment into MADDE was voluntary. Eligible applicants had to have a physician-certified diagnosis of an irreversible dementia, be enrolled in (or eligible for) both Parts A and B of Medicare, and reside in the demonstration site's catchment area. Two case management models were implemented. These differed by case manager-to-client ratios and per-month service expenditure ceilings for each client. Model A sites operated with a target case manager-to-client ratio of 1:100 and had a monthly community service reimbursement limit or cap of from $290-489 per month per client. Model B sites had a target case manager-to-client ratio of 1:30 and a slightly higher reimbursement limit of from $430-699 per month per client. Per month reimbursement caps in each model varied by site over time due to regional cost variations and inflation adjustments. Care usually covered under Medicare continued to be reimbursed as part of the regular Medicare benefit.

Case management and caregiver support services were covered by the program's administrative budget and were not included under the client's monthly expenditure caps. The support services included caregiver education and training, caregiver support groups, mental health and counseling services, and transportation to education and support groups.

Services reimbursed by the demonstration included adult day care; homemaker, housekeeping; general chore (i.e., heavy cleaning); personal care; minor home repairs; companion services; non-emergency transportation; adaptive and assistive equipment; consumable care goods (such as for incontinence); and safety modifications to the home.[1] Clients and/or caregivers paid a 20 percent co-payment for any demonstration services they used (for Medicaid participants the co-payment was waived).

Model A (low reimbursement-high caseload) sites were located in Champaign/Urbana, Illinois; Memphis, Tennessee; Portland, Oregon; and Rochester, New York. Model B (high reimbursement-low caseload) sites were located in Cincinnati, Ohio; Miami, Florida; Minneapolis,

[1] Additional, but seldom used, services included skilled nursing and rehabilitation nursing therapies (i.e., speech, occupational, physical; home health aide), medical supplies in conjunction with skilled and unskilled home care, and home-delivered meals not otherwise reimbursed by Medicare.

Minnesota; and Parkersburg, West Virginia. The demonstration became operational in December of 1989 and served clients and their families until November 31, 1994. Intake assessments were completed at the time of application to these programs. Applicants completing assessments were randomly assigned by the evaluators into the demonstration treatment group (where they were eligible for case management and service coverage), or into a control group (where they continued to receive their usual care). Persons receiving case management services at the time of application (for example, through Medicaid Home and Community-Based Care programs) were generally not accepted into the demonstration. These individuals were excluded because their case management and benefits were equal to or greater than that available through MADDE. Such exclusions occurred prior to randomization. Those becoming eligible for such programs after enrollment remained in the demonstration.[2]

Methodology

Four community services are included in these analyses: chore, personal care, companion, and adult day care. These were selected because they accounted for more than 80 per cent of the services used by demonstration participants (consumable supplies being the other most commonly used benefit). The hypotheses underlying the demonstration are (1) that treatment participants would have a higher likelihood of use of all these services relative to those in the control group; (2) that the intensity of service use among all users would be higher among those in the demonstration treatment group relative to controls; and (3) that participants in the Model B (i.e., higher resource) program would have both a higher likelihood and intensity of service use than participants in Model A (i.e., lower resource). Table 4-1 shows the variables used to represent predisposing, enabling, and need characteristics of an individual. These generally follow the conventional application of the Anderson-Newman framework (1973), client measures were expanded to

[2] Applicants during the first 24 months of operation constituted a closed panel of cases for the evaluation. The programs continued to enroll members for two years after that so they could maintain a steady-state client-to-case manager ratio. Evaluation data were not collected on these later enrollee cohorts. Miller, Clay, Fox, & Newcomer in Chapter 6 of this reort examine attrition from the MADDE project, finding no differences between treatment and control cases in mortality or other attrition rates.

include cognitive impairment, behavior problems, and type of housing. Caregiver attributes were added to the model and grouped into parallel predisposing, enabling, and need dimensions.

The predisposing characteristics of the caregiver (i.e., age, gender, and relationship) were selected from those found in other studies to influence the likelihood of service use. The enabling characteristics include measures that complement client attributes with regard to income, primary caregiving resources (i.e., time spent in this role, the availability of additional or secondary caregivers, and whether the caregiver lived with the client), whether the individual was a member of the demonstration's treatment group, and caregiver participation in both education and training about Alzheimer's disease and caregiver support groups. Caregiver need includes health status and functional limitations; as well as other situational dimensions of need like employment limitations (due to the caregiving role), perceptions of the client's functional needs for which the caregiver reports the need for additional assistance (i.e., unmet service needs) in providing ADL or IADL support, depression, and the stress/burden arising from caregiving itself.

The analysis controlled for the client's community of residence and service use in the months preceding the period of analysis. Community of residence adjusts for differences in the availability and cost of services among communities, and any practice pattern differences that may favor use of particular services. Prior studies suggest that the use of a service predicts subsequent use of the same service and that the resources used for one service (i.e., personal care) may compete against the use of other related services (i.e., adult day care). Controls were also used to adjust for differing lengths of exposure. The underlying logic was that longer time in the community after demonstration application could increase the likelihood of service use. Variables representing death or nursing home placement during the observation period were used to adjust for any unmeasured changes in health status or differential attrition associated with these events.

Insert Table 4-1 about here

The Study Sample

The analysis was conducted using data from the cohort of initial enrollees into the MADDE program. This cohort (n=5,831 cases) entered the demonstration between December 1, 1989 and

May 1, 1991, and included clients assigned to either treatment or control groups. Assessment data were collected at baseline and semi-annually on each of these cases if they continued to reside in the community.[3] The period for the analysis is the first 12 months after randomization. This period was selected because of the expectation that the case management intervention would likely have its greatest effect on clients during this initial exposure. In this sense the analysis is biased toward finding a case management/service reimbursement effect on community service use patterns.[4]

Three additional criteria were used for inclusion in this analysis. First, the client had to have a primary caregiver since caregiver predictors are a central dimension of the analytical question--136 did not have primary caregivers. Second, clients had to have been reinterviewed at the first semi-annual reassessment. This excluded 323 cases who died or were institutionalized within the first six months after enrollment. Third, clients could not be residing in supportive housing at baseline, because two of the four services examined were often provided in such facilities. This excluded 163 additional cases. Cases relocating into supportive housing after baseline were retained. A total of 5,209 cases met all of the sample criteria; 5,181 with no missing values.

Measurement

Service Utilization. To measure service use, primary caregivers were asked during each assessment interview to identify (from a fixed list of options) the services they had used in the prior six months, and to indicate how often they used them. If a person used the service in either the initial six-month period or during the first 12 months of the study, the case was classified as a service user (1 = use, 0 = non use). Caregivers were sometimes confused about how to distinguish personal care, chore, and homemaker services from each other. This was especially

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[3] A supplemental sample (n=2,310 cases) was drawn among applicants entering the demonstration between May 1 and November 1, 1991. This sample was selected to assure the evaluation of an adequate sample size for the full 36 months of exposure in the demonstration. For budgetary reasons, assessment data were collected only at baseline, 24, and 36 months for this group. The present analysis excludes this sample because community service utilization data during their first 18 months of enrollment were not collected.

[4] Further justification for this focus is provided by descriptive analysis of service use over the full 36-months. This revealed that differences in utilization patterns between the treatment and control groups were most pronounced during the first 12 months, but the groups did not converge over the remaining months.

true in the circumstance where a provider may have delivered more than one service (e.g., homemaker and companion) during a single visit. Respondents could typically identify total units and provide a percentage distribution of these units into the applicable categories. If a distinction could not be made, the respondent was asked to indicate the total units regardless of the type of service received during the period. Respondents were also requested to provide the names of service providers during the interview. During data coding, service type and agency were cross checked to distinguish care providers. When this procedure could not distinguish between types of services, the reported units were distributed equally among the applicable services. Care was taken to assure that service units were not double counted. Analyses were conducted treating each service separately, and combining companion, personal care, and homemaker/chore into a single measure of "any home care".[5]

Client and Caregiver Characteristics. Client and caregiver data were obtained from baseline and semi-annual assessment interviews conducted with the client's primary caregiver. Baseline and reassessment data provide client and caregiver attributes at a point in time, reassessments provide self-reported service use during the prior six months. Assessments were collected independently from the case managers by the demonstration evaluation contractors. Included among these data was client functional status as measured by a version of the Katz activities of daily living (ADL) scale (Katz, Ford, Moskowitz, Jackson, & Jaffee, 1963); Lawton and Brody's instrumental activities of daily living scale (Lawton & Brody, 1969); mental functioning was assessed using the 30 item Mini-Mental Status Examination (MMSE) (Folstein, Folstein, & McHugh, 1975); caregiver functional status measured as per client's above; caregiver burden measured by a revised version of Zarit's caregiver burden scale (Zarit, Reever, & Bach Peterson, 1980); caregiver depression measured by the brief version of the Geriatric Depression

[5]A comparison of self-reported community service use (among the treatment group), with the demonstration reimbursed claims found 93% of the cases were able to correctly identify that they were receiving a service when they were getting it, an equal proportion were correctly able to identify that they were not receiving a service (Donatoni, 1997). This finding was equally robust regardless of caregiver type (e.g., spouse, daughter, other family member), but reporting accuracy was higher among those living with the dementia client. Reporting of actual service units was much less reliable, but with no systematic bias. Any differential service unit reporting accuracy between the groups it is probably in the direction of having the treatment cases underreport units, because they had to pay for fewer of these services.

Scale (Yesavage, Rink, Rose, & Aday, 1983); and service utilization. Additional client and caregiver data included in the initial analyses were discussed earlier and are shown in Table 4-1. Among client predisposing, enabling, and need measures, the only difference between groups was that somewhat more women were in the control group. Among caregiver attributes the only significant differences were in caregiver hours per week (more among the treatment group), the task assistance from secondary caregivers (more among the controls), and receipt of caregiver training prior to enrollment (more among the treatment group).

Site Variables. Dummy variables representing each of the eight states participating in the demonstration project were used, with each of the included sites being coded relative to a reference site. The reference site chosen for each service (i.e., homemaker/chore, personal care, companion, and day care) was the one whose use rates were closest to the median percent of service users among all sites. This enabled comparison of any one site to the median performance of all sites in the demonstration.[6]

Alternative Service Use Control Variables. Separate analyses were conducted for the prediction of each selected community service (i.e., homemaker/chore, personal care, companion, and adult day care). If a study participant used the target service in the six-month period prior to enrollment into the demonstration, the case was classified as a baseline service user (1= yes, 0 = no). Each of the three other remaining community-based services were included in the model as control variables because the use of another community service could affect the use of the target service. Study participants were classified as a service user (1 = use, 0 = non use) for each of the alternative services if they used them in either the initial six-months or during the first 12 months after demonstration enrollment. For the regression analyses, units of service used in these periods

[6] Site visits were conducted at program start-up and close-out as part of the evaluation. One function of these visits was to interview local informants and program staff about service supply and issues relative to changes in supply, competitive advantage of the program to negotiate discounted rates, and problems in access to care for the dementia population. Except for placing Medicaid eligible recipients in nursing homes of their choice, there were no particular service access problems at either baseline or close-out. The programs were not large enough to stimulate new services (e.g., day care) available exclusively to the treatment group members, or to negotiate discounted prices. Any unmeasured "history" effects that may have influenced the applicant pool or the services they were able to obtain have been controlled within the study's prospective cohort by randomization of the applicants. Market area differences in access and use are reflected in the site and site by treatment interaction terms used in the analysis.

replaces the dichotomous variable. There were minor differences between the treatment and control groups at baseline in the likelihood of using chore service and companion services. These differences became non significant when all types of home care were combined. There were also minor differences in the average service use among users at baseline. These persisted even when the home care services were combined into a single measure.

Analysis

A two-stage model was used to test the hypotheses relative to the likelihood and amount of service use. The first-stage used logistic regression to identify the likelihood of any home care (and each of the component services, i.e., homemaker/chore, personal care, companion) and adult day care use. The second-stage model used bootstrap regression to identify affects on the amount of use among service users (Efron & Tibshirani, 1993). This resampling process was used instead of ordinary least squares regression because it makes no distributional assumptions about the residuals. Analyses had shown these models to have non-normally distributed residuals.[7]

Both the logit and the regression analyses were initiated using all the covariates shown in Table 4-1. Variables of substantive interest to the hypothesis testing were fixed in all models: experimental group assignment, site, site x treatment, three measures of client need (i.e., ADL, IADL, MMSE), and a measure of prior utilization for the service use outcome being predicted (e.g., prior chore service use as a predictor of chore service use during the first twelve months of the demonstration). Interaction terms between the client need variables and treatment and site effects were also tested, but not found to be significant. The final equation used in each model included all the fixed variables listed above and those measures that had met a .05 criterion in at least one of the earlier models. Only the treatment main effect, site, site by treatment interactions, and participation in caregiver training and support groups (if significant in the model) are shown.

[7] This procedure used 200 repeated estimations of each model, each using a random resample of cases with replacement, and then using the average of the parameter estimates and their standard errors as the model estimate.

Findings

Service Use Likelihood

Home Care. At the time of application to the demonstration, about one-fifth of the clients in both the treatment and control groups were using homemaker/chore services. During the first 12 months after demonstration enrollment, the proportion of clients who used homemaker/chore services increased substantially for both groups (see Table 4-1). The proportion of users more than doubled among those in treatment, while those in the control group increased by fifty percent. A similar pattern was apparent in personal care services. This includes assistance provided in the home for activities such as dressing, bathing, toileting, transferring, and eating. A third home care service, here termed companion services included friendly visitors, telephone reassurance, and adult "sitter services." Personal care worker or homemakers who provided shopping or errands might also have these tasks billed as companion service units. Companion services were designed to provide respite for caregivers, allowing them to leave the home and conduct personal business or social recreation activities. Prior to the demonstration, 17 percent of the treatment group and 14 percent of the control group had used companion services in the preceding six-month period. Like the other home care services, the proportion of use doubled among those in treatment and increased by half among the control group.

Recognizing that there may be problems associated with a client's ability to distinguish the definitional subtlety among these services, and that billing practices among providers or across sites may also cross over among the component activities, a variable "any home care" was created combining the units among the three types of services. This measure showed essentially identical use among the treatment and control groups at baseline. The rates of change over time approximated those of the component services.

Table 4-2 shows the result of a logit regression which controlled for site and treatment by treatment interaction effects on these results. As the results are similar among the component services and their combination, only results from the composite measure of any home care are shown. Being a member of the treatment group more doubled the likelihood of initiating home

care service, compared to membership in the control group. Community of residence had a marked effect on the likelihood of using this service in three of the eight communities during the first 12 months in the demonstration. Illinois was the site with the median percentage of use.

The interaction between site and treatment group was generally non-significant when home services were combined, suggesting that the difference between communities was usually a local practice phenomena rather than a treatment effect differential.[8]

Participation in caregiver training programs was associated with increased service use when all home care services are considered both together and separately. This effect was about half that of demonstration treatment group participation.

Insert Table 4-2 About Here

Adult Day Care. Adult day care offers from four to six hours of care at a center where supervised activities, health status monitoring, and a noon day meal were provided. Transportation to and from the center was usually included as part of the service. Prior to the demonstration, similar proportions (about 15 percent) of the treatment and control groups were users of day care services. Within 12 months this proportion doubled in the treatment group and increased by about 50 percent among the control group.

These differences are reflected in Table 4-2 where treatment group members were significantly more likely to use day care service than control group members. The likelihood of use relative to the median site (i.e., New York) was highest in Florida and Minnesota; and lowest in West Virginia and Tennessee. Site by treatment interactions showed no significant differences.[9] Experience with caregiver training had an effect on the likelihood of day care services approaching that of demonstration participation.

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[8] Combining home care services masks some of the variation among the specific services. For example, treatment group members were over 2.5 times more likely to use homemaker/chore services than control group clients in Tennessee; and almost two-thirds less likely to use homemaker/chore services than control group clients in Florida. New York treatment group members were almost two thirds (OR=.38) less likely, and Oregon 2.5 times more likely to use personal care services than those in the control group. Tennessee treatment cases were 2.2 times more likely, and Ohio treatment cases .23 times less likely than control cases to use companion services.

[9] The effect size for home care is about .44 and for day care about .33. The former has a power of .9 with as few as 170 cases, a number achieved except in the West Virginia site; the latter has a power of .8 with as few as 190 cases.

Amount of Service Use

The amount of home and community service use among those using a service either at baseline or sometime during the observation period does not appear to be particularly sensitive to treatment group participation as reflected in a simple comparison of mean expenditures in Table 4-1. The bootstrap regression results in Table 4-2, which control for site and site by treatment interactions, however do show a significant affect for both home care and adult day care. (Treatment affects on the individual home care services were not found.) On average, a treatment group member who used home care, used about 45 hours more than users in the comparison group. Similarly, treatment group members used on average about 7 more days of adult day care.

The amount of use of home care (among users) was significantly associated with only one of the eight sites, Oregon where the use was substantially below that of the median site (Illinois). There were no significant site by treatment interactions. With respect to adult day care, Florida had higher use than the median value site (New York); while Oregon was lower. Site by treatment interactions show Minnesota, alone among the sites, producing an increment of effect over the average main effect.

The general absence of statistically significant comparisons on both types of services is a function of the small effect size, .04 and .07 (the means divided by the standard deviation) for home care and day care respectively. Individual site level comparisons have a power level well under .20. For the total group of users, power is .3 and .4 respectively among the two types of services. Reductions in the standard deviation by 3/4's in home care and by 1/2 in day care would have increased the effect size to about .16, but even at this level a power level of .8 is achieved only with 1000 cases. For individual sites power would be no higher than .5.

Testing Demonstration Model Differences

Participation in the demonstration treatment group had a marked affect on the likelihood of service use. The third study hypothesis addressed whether participation in the Model B program (i.e., the higher monthly capitation) produced a higher likelihood of service use (and the use of more units of care) than participation in the Model A program. This question was addressed in a

series of models which differed from those in the prior analysis by the inclusion of a dummy variable where Model B cases were given a value of one, and the Model A cases were assigned the value zero. Step one of the analysis used the full set of covariates in Table 4-1 (including the treatment main effect), inserting the model dummy variable. Site and site by treatment interaction terms were omitted because model is correlated with site. Model was significant in this model. The second step reestimated these equations, retaining those items that met a criterion of .05, also adding site main effects and a model by treatment interaction term. This variable has a value of 1 when the model is B treated and 0 otherwise. The "model" dummy variable main effect was omitted due to its correlation with site. Logit and bootstrap regression results from this series of analyses are shown in Table 4-3. Of specific interest are the odds ratios for the model by treatment interaction, and the parameter estimates on the same variable. None of these results are significant within conventional criterion levels of $p<.05$. However, there was a tendency ($p<.10$) for Model B programs to have lower likelihood of home care, and increased likelihood of adult day care. Units of service received also showed a tendency for more units among those in Model B, but again at non significant levels ($p<.10$).

Insert Table 4-3 About Here

Discussion

There is a compelling pattern supporting the finding that the Medicare Alzheimer's Disease Demonstration treatment group participants had a higher likelihood of community service use than control group participants. This is consistent with the functions of the demonstration: working with families to identify service needs and to counsel them into appropriate services. Treatment group members were 1.7 to 2.3 times more likely than individuals in the control group to use home care services, each considered separately or 2.8 times more likely to use at least one of these services. The likelihood for adult day care use was 2.6 times higher among the treatment group.

Participation in caregiver training and/or support groups emerged as a naturally occurring, competing treatment in the experiment. Exposure to this support significantly increased the likelihood of community service use, approaching that of the demonstration program for adult day

care (i.e., odds ratios of 2.2 vs. 2.6). It was substantially lower for any home care use (i.e., odds ratio 1.4 vs. 2.8). This finding suggests the importance of training and counseling in affecting the willingness of caregivers to try a service.

The likelihood of using a particular home care service varied noticeably by community. This was expected given variations in the supply of providers and regulatory rules affecting eligibility. When the in-home services were grouped together--essentially treating these services as alternatives to each other--the variability across sites was greatly reduced, but not eliminated. Clients in both Tennessee and Florida showed higher propensities toward the use of in-home care than clients in the median site. Persistent site differences were even more apparent in comparing adult day care use likelihood. Clients in Tennessee and West Virginia, both of which had a substantial proportion of rural participants, were much less likely to use day care than clients in the median site. Clients in the predominantly urban sites of Florida and Minneapolis were substantially more likely to use this service. The general absence of significant site by treatment interactions suggests that the demonstration's main effect on home care and day care service use was relatively constant among all programs.

The higher rates of community service use among treatment group members, with the exception of adult day care, did not translate into a higher intensity of service use among those using the service. This finding, addressing the project's second hypothesis, suggests that while the demonstration's coverage for home care may have been helpful in getting more families to use a service, it was not sufficient to substantially alter the amount of service being used over that which was purchased through private out-of-pocket expenditures by control group members. In-home care services typically ranged in price from $12-$15 per hour, adult day care from $30-$55 per day. This translates into a monthly maximum of 24-40 hours of home care that could be purchased with the demonstration benefit for Model A and B clients respectively. This is equal to about one to two hours per day, five days a week, or more likely three to four hours on one or two visits per week. Day care is typically purchased in four to six hour blocks for a bundled price of about $40 per day. Given the benefit caps under each model, between two and three days of care per week

could be reimbursed under Model A and B respectively. These levels of support may be sufficient for routine client management, and appear to be affordable by a segment of the comparison group.[10]

The third hypothesis tested was whether participants in Model B (i.e., higher resource) would have a higher likelihood of service use and a higher intensity of use than participants in Model A (i.e., lower resource). This was tested in a series of analyses using a Model by treatment interaction term. There was a tendency for Model B programs to produce a higher likelihood of adult day care use, and an offsetting tendency toward lower likelihood of home care use, but these results were not statistically significant. These findings suggest that within the limitations of two sets of four site replications, there were few systematic differences among the two demonstration models. In other words, the combination of lower client to case manager ratios and up to $200 more per monthly reimbursement were not sufficient to produce demonstrably different utilization among the four replications of each demonstration model. Site differences within a model group offset most of the differences comparing between models.

An examination of the site by treatment interactions is informative for understanding the within and between group comparisons. Relative to the controls and the median site reference, treatment group clients in the low resource sites were as likely or more likely to be using a home care service as the treatment group clients in high resource sites. Part of this difference appears to be related to the prevailing practice in a community. Sites where prevailing use was low relative to the median site typically showed a tendency for increased use, as reflected in site by treatment interactions. The opposite occurred when the site was a relatively higher user of the service. These patterns appeared in both models. For adult day care, three of four Model B sites were above the median site in use compared to only one Model A site. All of the Model B site by treatment interactions (while not statistically significant) showed a tendency to further emphasize day care use or to be neutral to it. Half of the Model A sites, in contrast, showed a tendency to reduce use of this service.

[10] The unit price for these various services was not systematically higher in the Model B sites, which could have offset the financial advantage of Model B over Model A had such differences been present.

Summary and Conclusions

Three hypotheses were tested in this analysis: (1) that treatment group participants in the Medicare Alzheimer's disease demonstration would have a higher likelihood, relative to those in the control group, of using home care services (including homemaker/chore, personal care, companion) and adult day care in 12 months following voluntary enrollment into the demonstration; (2) that the intensity of community service use among all users would be higher among those in the demonstration treatment group relative to controls; and (3) that participants in Model B (i.e., higher resource) would have a higher likelihood of service and higher intensity of use than participants in Model A (i.e., lower resource). These hypotheses were tested using both logistic regressions of the likelihood of service use and bootstrap regressions predicting the level of use among service users. Applicants to MADDE were randomly assigned to treatment and control groups within each of eight demonstration sites. A common set of predisposing, enabling, and need characteristics of the dementia client cases and their caregivers was used for control variables.

The case management and community service reimbursement intervention had a strong, consistent, and positive effect on the likelihood of using each of the services examined. Treatment group clients were almost twice as likely to be using community-based services as were those in the control group. Caregiver training and support group participation increased service use likelihood's by at least 50 percent for two services.

Reimbursement for services provided through the demonstration's Medicare waiver facilitated the use of services but generally was not sufficient to exceed the level of service acquired by control group members through private payments.[11] In other words, it appears that the

[11] Quality assurance and satisfaction with the demonstration program may influence service use rates. The programs largely purchased services from existing and preestablished providers. The main exception involved attendant aides or home care workers, where neighbors, family members, and non-agency affiliated providers accounted for the bulk of the labor force. All sites worked with their major providers to influence staff training, often conducting training using the demonstration staff. They also tried to influence the assignment of staff to demonstration clients, such as by requesting the staff members that had gone through the training program or others found through experience to be of high quality. One site (West Virginia), set up its own home care program, recruiting, training and supervising home care staff. Quality assurance efforts per se, except in this latter example, continued to rest with the contracted provider and the appropriate licensing agency. Case managers did monitor whether the providers arrived when scheduled, and if the clients were reporting any problems or dissatisfaction with the providers.

relatively low reimbursement available was used primarily as a substitute for private payment, rather than as a supplement permitting more units of care. Two qualifications need to be made with respect to this finding. First, Medicaid eligible clients and caregivers were generally excluded from the demonstration at the time of their enrollment application. Thus the demonstration's effect was tested among a range of clients from the near-poor through people with progressively higher incomes. In this truncated range, low income may have been a contributing factor in non-service use. The demonstration's limited coverage may have been important in helping the near-poor population reach utilization levels more comparable to those of the moderate income population, but tests of treatment by income interaction terms were not statistically significant within the available sample size. This effect may have also been constrained by the 20 percent co-payment on demonstration services. Second, a weekly visit for personal care or homemaker/chore assistance or twice a week day care attendance, which was the norm among users, is essentially respite care. The increment from this respite level to one necessary to supplement daily care or 24-hour care needs was not tested by the reimbursement caps available from the demonstration. The effects of significant increments in funding on caregiver willingness to accept higher levels of assistance, and whether such a benefit reduces nursing home placement, are questions remaining to be tested.

One can draw conclusions about the relative effective of funding level differences between the demonstration's two models. Within the limits of the monthly payments and the case manager to client staffing ratios, it would appear that there is no systematic advantage for the high resource over the lower resource model when examined across the four sites in each model, although there is a tendency for the higher resource programs to emphasize adult day care. The finding of essentially equivalent impacts is important from a cost perspective. The low resource (Model A) sites have fewer service dollars to spend on each treatment client per month, and substantially lower administrative costs due to the client-to-case manager ratio (1:100 compared to 1: 30 for the high resource sites).

Participation in caregiver training and/or support groups emerged as a naturally occurring, competing treatment in the experiment. Exposure to this training or support approached the effect

of the demonstration program for adult day care selection. It was substantially lower for companion and chore care, and non-significant for personal care. Such a finding suggests the importance of training and counseling in care planning and in influencing the caregiver's willingness to try relatively unknown community services. An extension of volunteer support group resources could perhaps be an effective means of encouraging greater use of some community resources by caregivers. In this context it may be possible to reserve more extensive case manager involvement for reticent and complex cases. Such a triaging of caregiver needs was not an explicit component of this or similar case management demonstrations which have had to follow rather routinized protocols.

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Table 4-1
Characteristics of the Study Sample

Characteristic*	Treatment (n=2682) %	Treatment (n=2682) Mean	Treatment (n=2682) SD	Control (n=2527) %	Control (n=2527) Mean	Control (n=2527) SD
Client Characteristics						
Predisposing						
Age		78.5	7.8		78.7	8.0
Gender (female)	39.4			42.5*		
Minority (yes)	12.2			12.2		
Lives alone	13.1			13.7		
Type of residence						
Home/Condominium	85.4			83.8		
Apartment/Senior Housing	14.6			16.2		
Enabling						
Income						
Less than $9,999	34.0			33.4		
$10,000 - $24,999	38.6			38.9		
$25,000 and higher	27.4			27.7		
Need						
ADL Scale[a]		3.8	3.2		3.7	3.2
IADL Scale[b]		13.0	3.5		12.8	3.6
MMSE[c]		14.2	8.7		14.6	8.6
Behavior problems[d]		8.4	3.9		8.4	3.9
Service Use[e]						
Prior hospitalization[f]	20.9			21.0		
Day care days at baseline	16.4	19.5	35.2	15.0	29.7	40.4**
Day care days during year	37.1	78.1	67.9	21.1**	73.0	73.8
Chore care use/hours at baseline	17.8	40.9	125.6	20.0*	67.5	166.8**
Chore care use/hours during year	38.9	135.7	202.5	27.9*	139.4	260.3
Companion care use/hours at baseline	16.6	64.4	188.5	13.8*	83.00	199.1*
Companion care use/hours during year	37.8	174.6	294.0	21.4**	185.4	319.9
Personal care use/hours at baseline	19.7	90.2	232.3	18.9	104.1	242.6
Personal care use/hours during year	44.4	294.3	398.1	34.0*	295.6	426.1
Any Home Care use/hours at baseline[g]	42.8	114.0	259.1	42.3	134.7	263.2*
Any Home Care use/hours during year	74.8	353.3	497.4	56.6**	332.8	523.0
Assisted living housing use/days during year	5.5	161.8	107.9	7.7	161.2	107.2

* p<.05, ** p<.01 T-tests and chi-square analyses, as appropriate, were used to determine significant differences between groups.

[a] ADL score is based on clients needing none, some or maximum assistance. Scores can range from 0 to 10. Higher scores are indicative of greater impairment.

[b] IADL score is based on clients needing none, some or maximum assistance. Scores can range from 0 to 16. Higher scores are indicative of greater impairment.

[c] Mini Mental Status Examination values can range from 1 to 30. Lower scores are indicative of greater impairment. A score of 17 or under indicates moderate to severe impairment. Scores 18 to 23 indicate moderate to mild impairment.

[d] The Behavioral Problems Index ranges from 0 to 19. Higher score equals more behavior problems.

[e] Mean use of service is based on participants who used the named service at anytime during the year.

[f] Hospitalized in the 6 month period prior to entering the demonstration.

[g] Any Home Care is created by combining Chore, Companion, and Personal Care into a single measure

Table 4-1. Characteristics of the Study Sample (continued)

Characteristic*	Treatment %	Treatment Mean	Treatment SD	Control %	Control Mean	Control SD
Caregiver Characteristics						
Predisposing						
Relationship						
Spouse	51.2			51.3		
Married child	25.8			25.9		
Unmarried child	14.4			13.2		
Other relationship	8.7			9.6		
Age		63.8	14.3		63.6	14.5
Gender (male)	28.3			27.1		
Enabling						
Income						
Less than $14,999	28.8			29.2		
$15,000 - $29,999	39.8			37.3		
$30,000 and higher	31.4			32.3		
Lives with client	77.3			75.6		
Lives with spouse	48.3			48.4		
Hours per week caregiving		91.6	57.2		88.4	58.2*
Secondary caregiver assistance[j]		3.3	4.5		3.6	4.7*
Had used caregiver training services at baseline[n]	49.4			27.5**		
Needs (Caregiver)						
Health status (fair/poor)	22.9			23.9		
Functional limitations[h]		1.1	2.1		1.1	2.0
Employment limitations[i]	18.8			18.0		
Unmet service needs[k]		1.8	2.6		1.8	2.6
Stress and burden scale[m]		14.6	7.2		14.7	7.2
Depression scale[l]		4.4	3.4		4.4	3.3
Controls Variables						
Exposure days in period		308.0	93.9		304.3	97.3
Died during 1st 6 months of period	2.6			2.9		
Died during 2nd 6 months of period	5.8			5.8		
Nursing home placement 1st 6 months of period	10.9			12.0		
Nursing home placement 2nd 6 months of period	10.1			9.1		

* $p<.05$, ** $p<.01$ T-tests and chi-square analyses, as appropriate, were used to determine significant differences between groups.

[h] The mean number of ADL/IADL tasks the caregiver has some difficulty performing. Scores can range from 0 -13. The higher the score the greater the impairment

[i] The primary caregiver gave up employment related opportunities due to the caregiver role.

[j] The mean number of ADL/IADL tasks with which secondary caregivers provided help. Scores range from 0 - 13. The higher the score the greater the number of tasks secondary caregivers helped perform.

[k] The mean number of ADL/IADL tasks which the caregiver reported needing help. Scores range from 0 - 13. The higher the score the greater the unmet service needs.

[l] Scores range from 0 - 15. Scores greater than 5 reflect probable depression (Yesavage, et al., 1983).

[m] Scores range from 0 - 36. Zero to 8 scores represent low stress and burden. Scores 9-16 represent moderate stress and burden, 17 or more represents severe stress and burden. (Zarit et al, 1980).

[n] Caregivers had used either caregiver education and training classes and/or a caregiver support group in the 6 month period prior to entering the demonstration.

Table 4-2
Treatment and Community Effects on Service Use

Variable	Odds Ratio[a]	Wald 95% Confidence Limits Lower	Upper	Parameter Estimate[b]	Standard Error
Any Home Care Service (users n=3783)					
Treatment group	2.77	2.40	3.20	46.42	13.91***
Used caregiver training/support	1.40	1.20	1.61	-22.37	14.70
Low Resource Sites					
New York (n=590)	0.78	0.48	1.29	7.56	62.13
Oregon (n=673)	0.32	0.19	0.53	-209.20	52.16****
Tennessee (n=622)	2.67	1.64	4.36	173.50	90.09
High Resource Sites					
Florida (n=797)	2.42	1.53	3.84	83.56	47.91
Minnesota (n=891)	0.74	0.48	1.13	-51.73	42.84
Ohio (n=673)	1.11	0.69	1.78	78.76	59.40
West Virginia (n=400)	0.56	0.31	1.00	-101.67	66.34
Site x Treatment Interactions					
New York x treatment	1.06	0.52	2.16	-134.49	73.00
Oregon x treatment	1.74	0.85	3.55	1.18	58.61
Tennessee x treatment	1.93	0.88	4.27	-39.33	104.50
Florida x treatment	0.54	0.28	1.06	177.67	66.74
Minnesota x treatment	1.13	.62	2.06	2.81	56.86
Ohio x treatment	0.38	0.19	0.73	-103.52	70.28
West Virginia x treatment	1.90	0.76	4.71	111.29	87.76
Adult Day Care Service (users n=1697)					
Treatment group	2.61	2.20	3.10	7.12	3.45*
Used caregiver training/support	2.23	1.92	2.60	5.71	2.90*
Low Resource Sites					
Illinois	1.10	0.58	2.08	28.55	14.83
Oregon	0.52	0.26	1.03	-48.66	10.98****
Tennessee	0.39	0.18	0.86	-14.16	19.93
High Resource Sites					
Florida	2.73	1.55	4.80	38.40	12.24**
Minnesota	4.58	2.79	7.51	7.49	9.24
Ohio	1.80	0.96	3.37	10.14	13.22
West Virginia	0.16	0.05	0.49	-12.35	27.85
Site x Treatment Interactions					
Illinois x treatment	0.85	0.38	1.92	-12.38	18.07
Oregon x treatment	0.43	0.18	1.04	7.49	14.06
Tennessee x treatment	1.33	0.50	3.59	-21.60	25.64
Florida x treatment	0.94	0.46	1.93	-4.67	14.08
Minnesota x treatment	1.21	0.63	2.30	30.47	11.57***
Ohio x treatment	1.50	0.69	3.26	1.98	15.55
West Virginia x treatment	2.07	0.56	7.63	9.84	30.84

Statistical Significance * p<.05, ** p<.01, *** p<.001, **** p<.0001

[a]Odds Ratio refer to the logit analysis.

[b]Parameter estimate refers to the bootstrap analysis of service users.

Illinois (n=641) is the reference site for the any home care comparison; New York for the day care comparisons

Any Home Care Logistic regression R^2 .23, w/ 32 d.f; Bootstrap regression R^2 .29, F Value 13.015.****

Adult Day Care Logistic regression R^2 .30, w/ 39 d.f.****; Bootstrap regression R^2 .36, F Value 21.669.****

Table 4-3
Testing Model A vs. Model B Effects on Service Use

Variable	Odds Ratio[a]	Wald 95% Confidence Limits Lower	Upper	Parameter Estimate[b]	Standard Error
		Any Home Care			
Treatment group	3.05	2.50	3.72	23.71	21.53
Used caregiver training/support	1.38	1.19	1.59	-23.60	16.32
Low Resource Sites					
New York	0.72	0.49	1.06	-42.85	45.49
Oregon	0.38	0.26	0.56	-178.18	33.45****
Tennessee	3.16	2.12	4.71	179.93	60.16**
High Resource Sites					
Florida	2.04	1.42	2.93	153.03	38.93***
Minnesota	0.90	0.64	1.25	-77.04	30.35**
Ohio	0.77	0.54	1.11	-7.12	44.14
West Virginia	0.82	0.52	1.29	-65.85	50.37
Model x Treatment Interaction					
Model B x Model A & Controls	0.79	0.60	1.03	48.66	28.48
		Adult Day Care			
Treatment group	2.19	1.73	2.76	2.60	4.60
Used caregiver training/support	2.23	1.91	2.59	5.33	2.92
Low Resource Sites					
Illinois	1.14	0.74	1.77	27.82	9.41**
Oregon	0.38	0.23	0.61	-37.54	8.08****
Tennessee	0.54	0.33	0.91	-20.66	10.85
High Resource Sites					
Florida	2.26	1.48	3.43	29.02	8.18***
Minnesota	4.30	2.98	6.20	19.69	7.09**
Ohio	1.91	1.26	2.91	4.11	7.93
West Virginia	0.22	0.12	0.41	-12.98	15.19
Model x Treatment Interaction					
Model B x Model A & Controls	1.30	0.98	1.80	10.88	5.99

Statistical Significance $^{*}p<.05$, $^{**}p<.01$, $^{***}p<.001$, $^{****}p<.0001$

[a]Odds Ratio refer to the logit analysis.

[b]Parameter estimate refers to the bootstrap analysis of service users.

Model B (i.e., Higher Resource) Sites treated group (n=1423), Model A treated group (n=1259), Controls (n=2527)

Any Home Care Logistic regression R^2, .22 w/ 25 d.f. **** Bootstrap regression R^2 .29, F Value 11.050.****

Adult Day Care Logistic regression R^2, .30 w/ 31 d.f. **** Bootstrap regression R^2 .36, F Value 27.607.****

Chapter 5

The Effects of the Demonstration on Caregiver Burden and Depression

by

Robert Newcomer, PhD[1]
Cathleen Yordi, DSW[1]
Richard DuNah, MA[1]
Patrick Fox, PhD[1]
Anne Wilkinson, PhD[2]

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[1]University of California, San Francisco
[2]George Washington University

Abstract

Study Question. Does improved access to community-based care reduce perceived burden and reported levels of depression among primary caregivers of people with dementia?

Data Sources. Baseline and periodic caregiver interviews were obtained from participants in the Medicare Alzheimer's Disease Demonstration. Client and caregiver attributes and caregiver outcomes such as depression and burden scores were among the measures.

Study Design. Voluntary applicants to the demonstration were randomly assigned into treatment and control groups. Treatment group cases were eligible for case management, and up to $699 per month in community care benefits (the actual monthly entitlement varied among the eight demonstration communities due to regional cost differences and inflation adjustments over the four year demonstration period).

Data Collection. A total of 5,307 eligible individuals received a baseline assessment at the time of application to the demonstration and at least one semi-annual reassessment. Clients and their caregivers were periodically reassessed producing a total of 20,707 observations.

Principal Findings. Treatment group cases had a high exposure to case management and a greater likelihood of community service use relative to those in the control group. Treatment group membership was associated with statistically significant, but very small reductions in caregiver burden (in four of eight sites) and depression (three of eight sites) over a 36-month tracking period. These findings are not sustained with all cases combined, or among a higher resource demonstration model considered separately.

Conclusions. Both the fact that these programmatic differences did not translate into substantial treatment group reductions in caregiver burden or depression, and the consistency of these findings with those of prior case management evaluations suggest the need to reformulate this programmatic intervention into areas not previously tested: 24-hour care, crisis intervention, coordination with primary care or chronic disease management.

Key Words. Dementia, case management, caregiver depression, caregiver burden.

The care of persons with Alzheimer's disease and related dementias is known to be a particularly challenging responsibility for family members. This results from the terminal nature of the illness and its preceding mental decline, loss of independence, and increasing need for supervision and assistance (e.g., Duijnstee, 1994; Vitaliano, Young & Russo, 1991). An estimated four million American adults suffer from Alzheimer's disease or other forms of dementia (Evans, Scheer, Cook, et al., 1990), and about half of the nursing home population has dementia (Rovner, Kafonek, Filipp, Lucas, & Folstein, 1986).

Caregivers of people with dementia have been shown to experience depression, anger, anxiety, and guilt, and to report negative attitudes toward the patient and other family members (cf., George & Gwyther, 1986; Schulz, Williamson, Morycz, & Biegel, 1993). The responsibilities of caregiving often constrain social participation, in some cases necessitate withdrawal from the work force (cf., Scharlach, 1994; Stone & Short, 1990), cause disruption of family relationships, and even deterioration of the caregiver's physical health (cf., 1986; Pruchno & Resch, 1989; Zarit, Pearlin, & Schaie, 1993). These negative effects are collectively referred to as caregiver burden.

In response to the documented problems experienced by caregivers, the Health Care Financing Administration implemented a case management and community care program for dementia victims and their caregivers (section 9342 of the Omnibus Budget Reconciliation Act of 1986) known as the Medicare Alzheimer's Disease Demonstration Evaluation (MADDE).[1] This program was financed through an augmentation to regular Medicare benefits. Application to the program was voluntary. Eligible applicants were randomly assigned to treatment and control groups. Caregivers in the treatment group were given access to education and training about Alzheimer's disease and related topics, both through one-on-one interactions with case managers and through caregiver support groups. This contact was intended to aid in reducing caregiver isolation and loneliness, provide an opportunity to share feelings and experiences in a supportive environment with peers who shared similar concerns, provide caregivers with specific information

[1] The locations, benefit structure and other operational features of the program are discussed in Chapter 2 and Appendices 4 and 5 in this report, sample attrition after randomization is discussed fully in Chapter 6.

environment with peers who shared similar concerns, provide caregivers with specific information about how to care for a person with dementia, and exchange approaches in how to cope with the stresses and burdens of caregiving. Case managers also informed caregivers about formal services in the community, assisted in determining an appropriate service package to meet the client's needs, coordinated formal assistance in caregiving tasks, and monitored the quality of services provided by demonstration service providers.

This paper is one in a series of MADDE reports on the intervention's ability to affect caregiver outcomes. In analyses reported elsewhere in this HSR issue, treatment group members are shown to have experienced a substantially increased likelihood of using community services (Newcomer, Yordi, Fox, & Spitalny, in press). Other work has shown that treatment group caregivers consistently reported fewer unmet needs for assistance in providing support to the demented person in activities of daily living (ADLs) and instrumental activities of daily living (IADLs) (Yordi, DuNah, Fox, Wilkinson, & Newcomer, in press). Access to more and appropriate assistance was expected to reduce reported levels of burden and depression among primary caregivers of people with dementia. Assessing whether the demonstration achieved these outcomes is the subject of this analysis.

Study Design

Two case management models were implemented. These differed by case manager-to-client ratio and per-month service expenditure ceilings for each client. Model A sites operated with a target case manager-to-client ratio of 1:100 and had a monthly community service reimbursement cap of from $290-$489 per client. Model B sites operated with a target case manager-to-client ratio of 1:30 and had a slightly higher monthly cap of from $430-$699 per client.[2] The reimbursement caps in each model varied within these ranges by site over time due to regional cost variations and inflation adjustments. Clients and/or caregivers paid a 20 percent co-payment for any

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[2] Four sites operated under Model A (low reimbursement-high client ratios) and four operated under Model B (high reimbursement-low client ratios). Model A sites are located in Champaign/Urbana, Illinois; Memphis, Tennessee; Portland, Oregon; and Rochester, New York. Model B sites are located in Cincinnati, Ohio; Miami, Florida; Minneapolis, Minnesota; and Parkersburg, West Virginia.

demonstration service they used, except for Medicaid participants for whom the co-payment was waived.[3]

Case management and caregiver support services were covered by the program's administrative budget and were not included under the client's monthly expenditure caps. The support services included caregiver education and training, caregiver support groups, caregiver/family mental health and counseling services, caregiver transportation to education and support groups, and caregiver and client case management.

The demonstration became operational in December of 1989 and served clients and their families until November 31, 1994. Intake assessments were completed at the time of application to the demonstration. After completing the intake assessment applicants were randomly assigned by the evaluators into a treatment group (where they were eligible for case management and service coverage), or into a control group (where they continued to receive their usual care).[4] A total of 8,138 eligible individuals received a baseline assessment at the time of application to the demonstration. Excluded from the present analyses are 189 clients who did not have an informal caregiver at baseline, and consequently provided no basis on which to assess caregiver outcomes. The rates of change (i.e., slope estimates) developed in the analysis are based on the presence of at least two data points for a case. For this reason 2,642 cases were excluded who had only a baseline assessment, and who did not remain in the community (because of death, nursing home placement, withdrawal from the demonstration, or change in caregiver between the baseline and first reassessment) through a second assessment period.[5] These exclusions leave an analytical

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[3] Services reimbursed under the demonstration included adult day care; skilled nursing and rehabilitation therapies (i.e., speech, occupational, physical; home health aide) not otherwise reimbursed by Medicare; homemaker/personal care; housekeeping; general chores (i.e., heavy cleaning); home repairs and maintenance; companion services such as friendly visiting, caretaker care while the caregiver attends educational and/or support groups; home-delivered meals; non-emergency transportation for the client; adaptive and assistive equipment; medical supplies in conjunction with skilled and unskilled home care; consumable care goods; and safety modifications to the home.

[4] No restrictions were placed on a participant's ability to use community services after enrollment. Persons who were receiving intensive case management services at the time of application from, for example, Medicaid Home and Community-Based Care programs, were generally not accepted into the demonstration. This exclusion was made because these individuals were already receiving a level of case management at least comparable to the demonstration and were eligible for a benefit package that was more extensive than that offered through MADDE. In otherwords, such cases had no likelihood of benefiting from MADDE participation. All such exclusions occurred prior to randomization.

[5] The attrition from the project is reported elsewhere in Chapter 6, examining nursing home placement and mortality

sample of 5,307 clients who received a baseline assessment and up to five reassessments over the 36-month study period--a total of 20,707 observations. Cases are included in these analyses only for their period in the community because they were disenrolled from case management and community care benefits after a permanent nursing home stay. At the end of the three-year study period, 36 percent of the initial sample were residing in the community and received a 36-month reassessment.[6]

Conceptual Model

The Pearlin stress process model (cf. Pearlin, Mullen, Semple, & Skaff, 1990) was used to guide variable selection for the caregiver well-being analyses. This framework views stress in three major domains: stressors (i.e., the conditions and experiences that have the capacity to arouse states of stress), mediators (i.e., those actions and resources that have the capacity to influence the direction of the stress process and blunt its impact on caregivers), and outcomes (i.e., psychological distress, physiological status, etc.). The stress process framework focuses on the primary caregiver as the unit of analysis and proposes that differences in levels of stressors, psychosocial resources and personal dispositions directly and indirectly influence adverse stress-related outcomes. Key social and economic characteristics of caregivers, such as gender, ethnicity, and age are among the variables contained within a contextual factors domain. 5-1 summarizes the measures used in the analysis, grouped under Pearlin's conceptual domains. We have elaborated his framework to include the experimental variables, community of residence, attrition adjustments for length of program exposure, and enrollment cohort to adjust for program maturity. The outcomes of interest are described below.

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rates. This work has shown no differential attrition from either treatment or control group.

[6] The slope terms estimated in the analysis use all cases that contributed at least two data points. These estimates become more stable with the use of more than two observations. Statistical power has been calculated for observations as the unit of analysis. For burden scores, using the mean value of 14.5 and a standard deviation of 8.5 (as shown in Table 5-2), a 1 point difference between groups (an effect size of .12) gives the project a power greater than .80 with an alpha of .05 (one-tailed) for as few as 1800 cases per model or between treatment and control. Site level analyses have a similar power with a 2 point difference in scores. Comparable effect sizes also occurred for depression (which is equal to a .5 point difference from a mean depression score of 4.5 and a standard deviation of 3.6 (as shown in Table 5-2), producing similar power levels within the number of sample subjects.

Caregiver Burden was measured using an adaptation of a scale developed by Zarit, Reever, and Bach-Peterson (1980). The scale, in which eight items were summed with responses ranging from (0) Never to (4) Always (alpha = .852), included items that asked caregivers whether they felt stressed between caring for the client and meeting other family responsibilities, and between caring for the client and having enough time for themselves; whether they felt angry around the client; whether they felt tense or anxious due to involvement in caregiving; whether they felt their health had suffered due to caregiving; whether their social life had suffered; whether they felt they had lost control of their life since the client's illness; and how burdened they felt in caring for the client.

Caregiver Depression was measured using the short-form Geriatric Depression Scale (Yesavage, Rink, Rose, & Aday, 1983). The scale sums affirmative responses to 15 items (alpha = .798), which asked caregivers whether they were basically satisfied with their life, had dropped many of their activities and interests, felt their life was empty, were often bored, were in good spirits most of the time, felt helpless, preferred to stay home or go out and do new things, felt they had more problems with memory than most people, thought it was wonderful to be alive, felt worthless, were full of energy, felt their situation was hopeless, and thought that most people were better off then they were.

Analytic Methods

The hypothesis that participation in the case management and community services intervention would reduce perceived caregiver burden and depression was tested using a two-stage hierarchical linear model (HLM) (Bryk & Raudenbush, 1992). This method permitted testing of the effects of the independent variables of interest (i.e., treatment group assignment, experimental model type, and community of residence) on caregiver outcomes, controlling for caregiver and client characteristics. In these analyses, the first HLM modeled individual-level change in caregiver burden and depression levels as a function of time (i.e., the observed exposure period as a caregiver). The intercept in this model was the baseline burden score (or depression as appropriate) for the individual, and the slope term was a rate of change centered on the new period

less the baseline burden (or depression) value. The level-one analysis yielded an intercept and a slope for each caregiver. These were then used as the outcome measures in a second-level, or between-person, model. In this second-level model, client and caregiver characteristics (see Table 5-1 for a listing of variables and their means) were used to help account for between-individual differences in the trajectories of change. The treatment, experimental model, and community location measures were included in some analyses in a level two rather than in a level-three between-group comparison model. In other analyses, separate estimates were modeled for each community and by demonstration model. A three level model was not used because of the small number of conditions that form this level (two in the case of experimental groups, eight in the case of sites). A minimum of 15 groups is needed to obtain reliable statistical estimates (Bryk & Raudenbush, 1992). Adjustments for model and site were addressed by running separate HLM models for Model A and Model B and for each individual site.

The intercept for each individual in level two is equal to the estimated baseline value of the outcome measure for that individual. Bryk and Raudenbush (1987) showed how this modeling framework can supply estimates of the mean trajectory, of individual variation around the mean, of the reliability of measures of change, of the correlation between true status at any time and true rate of change, and of correlates of change.

HLM has several advantages for this evaluation: 1) it does not require the time between assessments to be equivalent; 2) subjects who did not participate in the study for the entire three-year time period can be included in the analysis; and 3) any differential effects of site or model level variables on caregiver outcomes can be assessed.

The control group is the referent group for all treatment/control comparisons presented. A difference between treatment and control groups is tested in the level-two HLM as the between-person estimated slope adjusted for caregiver and client attributes, site location, and treatment participation. A negative difference on the treatment coefficient indicates that the slope (or rate of change) is lower for the treatment group.

The following HLMs were calculated for each outcome measure:

- To test the overall treatment effect regardless of model, an HLM was calculated with all control variables, and measures representing model (A or B), and treatment group.
- To test for a greater treatment effect for Model B sites compared with the Model A sites, a separate HLM was estimated for each demonstration model. Each HLM controlled for site differences in addition to the other control variables. Separate HLMs were necessary because treatment site and demonstration model were confounded. Each site was assigned to be either Model A or B, and subjects were therefore not randomized to Model A or B. This confounding prevented testing model effects while controlling for site effects. Separate HLMs for each program type, controlling for treatment site within each model, eliminated the confounding problem.
- To test whether there were site-level differences in treatment effects, the difference between the treatment and control groups at one site was compared with the average difference between the treatment and control groups at the other sites. This comparison was accomplished by creating seven effects-coded dummy variables to represent the eight different sites, and then interacting each of these variables with the treatment and control group variables. The HLMs for each outcome measure were then calculated using the site dummy variables in place of the model variable.
- To test for a differential effect for those in the study with various characteristics (e.g., was the intervention more effective for older caregivers than younger caregivers), interaction terms between control variables and the treatment group variable were added to the variables listed in the first set of equations above.
- Because the site by treatment group interactions accounted for a significant reduction in the amount of variance, separate models were also run for each site.

To control for any possible attrition bias, two variables were included in all of the HLMs: number of months in the study (ranging from 6 to 36) and client enrollment cohort (four groups of equal size based on date of entry to the study). This latter variable adjusted for program maturity

and any unmeasured differences in the program applicants occurring with the length of the program's operation.

Table 5-1 shows the client and caregiver characteristics of the study sample at baseline on each of the control variables included in the analysis. The treatment and control groups were equivalent at baseline on all of the independent variables.

Table 5-1 here

Findings

Unadjusted Caregiver Outcomes at Each Reassessment

Table 5-2 presents unadjusted mean scores on the caregiver burden and depression scales at baseline and at each reassessment interval. The data for mean caregiver burden show a statistically significant difference between the levels of burden in the treatment and control groups at the six-month interview period (mean scores of 14.4 versus 14.9, $p < .05$). A statistically significant difference in burden between the treatment and control group is absent in the other periods.

Caregiver depression is not statistically different between treatment and control groups at baseline, 6, 12, and 36-month reassessment intervals. There are statistically significant differences at the 18 and 24-month reassessment intervals. A score of 8 or more on the depression scale suggests clinical depression. Persons one standard deviation from the mean approached this threshold in both groups, leaving about 17 percent of the sample in each group with possible clinical depression.

Table 5-2 here

These findings, given the successful randomization of treatment and control groups, provide a strong indication that the treatment on average did not substantially reduce caregiver burden or depression.

Effects of the Intervention: Assessing Change Over Time

Table 5-3 summarizes the HLM results from the level two models described previously. The rows in this table show the intercept and slope coefficients for the relevant study question: tests of treatment effect, model effects, and site effects. These results were each obtained from separate analytical runs. Each run included all the covariate measures shown in Table 5-1, but for

brevity the covariate coefficients are not shown. The slope terms are given in outcome measure units per month. The difference between the treatment and control groups at 36 months can be computed by multiplying the slope differences per month by 36 months and adding the result to the intercept difference. These combined values are shown in the last column of the table.

Caregiver Burden: The upper half of Table 5-3 presents the results of the HLMs for caregiver burden. The mean intercept for this analysis was 14.33, which is approximately equal to the mean score across all individuals on the burden measure adjusted for caregiver and client attributes at baseline. The average rate of increase in burden for the sample was .012 units per month, or .43 over the three-year duration of the study (mean slope .012 x 36 months). The mean change in burden score, comparing the slope treatment and control group differences for the full sample combined (row two), suggests a tendency for a modest reduction (i.e., -.011) among the treatment group, but this rate of change is not statistically different from that of the control group.

Table 5-3 about here

To refine the test of whether there was a difference in treatment effect on caregiver burden between the demonstration models, separate HLMs were run with Model A and Model B samples, respectively. These results are shown in rows 3 and 4 of the table. There was no significant treatment effect within either sample relative to the controls. The relative performance of one model with the other is not tested directly, because of the many local factors affecting service use and practice variation. However, an indirect comparison, adjusting for local characteristics, was compiled through a third set of analyses where the relative performance of the treatment program effect is evaluated within each site. The results are shown beginning with row 6 of the table. Each row reflects the adjusted rate of change (i.e., slope) for the treatment/control differences in that particular site. The covariates used in these models were again those in Table 5-1.

These analyses show a significant treatment effect on caregiver burden in two Model A sites: Illinois (slope difference -.085) and Tennessee (slope difference -.044). For Illinois this translates into a greater than four point difference in burden scores relative to the controls after 36 months. The difference is just less than one point in Tennessee. A third site, Oregon, reported an

increase in burden among treatment participants (slope difference = .056), or about 1.5 points on the burden scale. In the Model B sites, the Minneapolis site achieved a significant treatment effect on caregiver burden (slope difference = -.038), a 1.3 point difference relative to the controls after 36 months. There were no other statistically significant differences among the other Model B sites.

Caregiver Depression: The bottom half of Table 5-3 summarizes multiple sets of HLMs for caregiver depression and is organized in a manner parallel to the burden results. The mean intercept for the HLM conducted for the depression analysis was 4.23 (row 15), a value approximately equal to the mean score on the depression measure at baseline. The model adjusted rate of increase in depression for the sample was .013 units per month, or about .5 units over the three-year duration of the study (mean slope .013 x 36 months). The comparison of treatment effects on the rate of change with all samples combined is shown in row 16. This analysis shows a statistically significant difference in the rate of decline in depression score between the treatment and the control groups (slope difference -.009), about .4 units less for the treatment group than the control group at 36 months.

Rows 17 and 18 refine the preceding result through comparisons of each demonstration model. Analyses of the Model A and B samples used the fully specified HLM (i.e., the covariates in 5-1). These results show a significant treatment effect for Model A (slope difference = -.013), but not for the higher resource Model B.

Fully specified HLMs were run for each site to test whether between-site variation may mask treatment effects in each model. These results are summarized beginning with row 20. About a 1.6 unit treatment reduction on caregiver depression was found in Illinois (slope difference = -.031, plus the intercept term), and just less than a half unit decrease in caregiver depression in the treatment group was found in Tennessee (slope difference = -.020). There were no significant differences in the other two Model A sites. Among the Model B sites, only Ohio showed a significant difference between treatment and control groups--about a 1 unit reduction in depression scores.[7]

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[7] As a test against the possibility that prevailing levels of depression and burden were too low to be sensitive to an aggregate mean difference test, distributed the cases above a defined limit (e.g., 8 or more for depression; and by

Discussion

The Medicare Alzheimer's Disease Demonstration was a complex, multi-factorial intervention, combining case manager involvement with clients and caregivers, caregiver training, and community long term care service reimbursement. It involved voluntary applicants. Demonstration treatment group participants were more likely than control group participants (i.e., 50 percent vs. 40 percent) to use community services (e.g., personal care, homemaker, companion, and adult day care) (Newcomer, et al., in press). These service access accomplishments, if they are related at all to the demonstration's effect on caregiver outcomes, translate into only modest reductions in caregiver burden and depression levels. With all sites combined, there is less than a one-point difference between treatment and controls for burden (on a 32 point scale), and less than half a point difference on depression (a 15 point scale). Analyses of each community suggested a modest trend of reduced burden and depression among treatment group members, but statistical significance was achieved in only about half the sites. Differences were usually under 1.5 points on the burden scale and less than 1 point on the depression scale.

Treatment group cases receiving community-based long term care services reported similar levels of service to those in the control group (see Newcomer, et al., elsewhere in this HSR issue). Perhaps higher levels of care would have changed these results among users, but in this comparison of an "intention to treat" group, a higher likelihood of use did not substantially alter the mean burden and depression scores among the samples.

This finding of little impact on caregiver well-being over 12 months or longer of program participation is consistent with most evidence from evaluations of other home and community-based demonstrations (cf., Weissert, Cready, & Pawelak, 1988).

Several observations from the current study can be added to the list of reasons why so few intervention effects have been found. First, caregivers are to a large extent self-selected into these roles. While a spouse is the most prevalent caregiver, other family members generally assume

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quartiles among the burden scores) and tested whether there was a treatment and control difference in the mean change score between baseline and 12 months for each of these subgroups. These results show no treatment effect on either the possible depression group or those below this threshold, and only a 1 point difference among the highest quartile of the burden group.

primary caregiver roles if the spouse-caregiver is (or becomes) unable to assume or maintain this responsibility. Absent such adjustments, the client enters a nursing home. One implication of this is that evaluative analyses have to find outcome variance (in this case in caregiver burden and depression) in a caregiver system that may be making constant adjustments to remain at a viable level of capacity. A corollary to this observation is that family adjustments apparently can and are made by many of the affected families without the intervention of a professional case manager--further dampening the outcome variance that could be interpreted as an intervention effect. A third observation is that families on average are reasonably able to tailor or target the level of home care needed to assist in their role. In this program, with the relatively low monthly benefit waiver, only about 20 percent more of the treatment group cases received community care than did individuals without case managers or access to the benefit coverage, a finding consistent with the experience of Channeling and other community care demonstrations (cf., Weissert, 1988). A fourth observation is that the measurement period used in this and most other case management demonstrations may be too arbitrary. Case managers may be most helpful to families in times of crisis or transition, such as following a hospitalization or illness, or when problems arise in living arrangements or with formal care providers. The consequences of any assistance given at these junctures are not measured well with a fixed six-month cycle of reassessments and caregiver interviews Consequently, it is possible that the current results underreport the true treatment effect.

Three questions arise from this observation. First, if case management is helpful in these transitional/crisis periods, do policy makers and health care payers care that the usefulness is time limited (i.e., not carrying over for six-month measurements), and that the absence of assistance is self-correcting (i.e., adverse stress and other concerns do not carry over for six-month measurements)? Second, could case management be more effective in providing crisis care? Third, if crisis intervention is effective, is there any way to cost effectively target cases for such assistance, or intervene before the crises occur?

Each of these explanations (or combinations of explanations) as to why a more notable treatment was not achieved may contain substantial elements of validity. These issues speak to

design and implementation issues in future interventions. A number of policy, practice, and research conclusions can be drawn from this research:

- The benefit cap, while not insignificant at $299 to $699 per client per month, appears to have been too low to substantially increase the amount of formal care used by the treatment group compared to the amount of services purchased by those in the control group. Utilization rates and intensity of use varied more by community than by demonstration models. The upper limit of the community care benefit needed to produce major service use differences within a treatment program was not tested in MADDE, but it should be noted that the Channeling Demonstration used a maximum benefit that was set at 60 percent of the monthly cost of a nursing home stay (substantially more than the MADDE reimbursement caps) and produced no better outcomes.

- The pattern of the demonstration's effect measured in terms of caregiver burden and depression varied substantially across communities, but with mean differences between treatment and control groups in each community that had questionable clinical significance. Given that two of the three sites showing statistically significant differences between treatment and control groups were in the low reimbursement/high case load model, the conclusion might be drawn that there is no particular advantage to the 1:30 model as implemented in terms of affecting caregiver burden and depression.[8]

- The demonstration program provided services to people with dementia or to their caregivers that did not substantially differ from the types of services already available to members of the control group. Had the intervention attempted to provide a more unique set of benefits, perhaps the result would be more striking. As an example, the demonstration's benefit reimbursement levels were much too low to provide a wide range of services that were accessible twenty four hours a day, seven days a week, or to provide such intensive services for even short periods. Would such service intensity make a difference in caregiver outcomes? This issue is untested by this demonstration.

- This program operated outside of an integrated health care system. With the exception of the Illinois site, all programs operated from social service agencies and were staffed by social workers (although nurse consultants were usually available). The Illinois site was located in a large multi-specialty health group, and was staffed exclusively by nurses. This may have given this particular site more ability to assess changes in health status and to respond to health care crises more rapidly. This site had the most impressive effect on reducing caregiver burden. The nature and focus of case manager activity relative to crises and health status issues need further examination and perhaps experimentation. An element completely ignored by this demonstration was the coordination of case manager and primary care physician activities. This was not an explicit focus in any site--nor an expectation of the demonstration. This is also an area for future study.

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[8] An alternative test of the model differences would have pooled all the sites together within each respective model and then computed statistical tests on Model A vs. B comparisons. We have done this to a limited extent, in that sites were pooled within a model and comparisons to treatment and control effects tested. These results showed that site differences were stronger than model differences. We did aggregated the sets of sites together and then compare models with each other. We did not do this because study subjects were randomized within sites, not by model. In other words pooling the sites together moves the study from a randomized experiment to a quasi-experiment, and raises concerns about the fairness of judging a model by the mix of programs comprising it, and whether we were able to appropriately model the selection-choice factors and the vast practice pattern "within group differences" among the sites in model. In our judgment results with these multiple sets of adjustments and assumptions are less believable and interpretable than results that simply look at the individual performance of the programs in each model, as we have done. Sample size is sufficient for site level analyses.

- Case management was largely oriented to assessment, client monitoring, care planning, and situational problem solving. Unlike home health care managers and private long-term care case managers, the demonstration's case managers generally did not have a direct role in the training or supervision of home care workers. Whether such a role would have afforded them better opportunity to assure high quality care and to help avoid situational crises is untested. Coordination with primary care providers may also have practical relevance, whether within managed care systems or not..

- The finding of only a marginal demonstration effect on caregiver burden and depression levels was affirmed in multiple comparisons among sites, models, and time intervals. Nevertheless, it is possible that the demonstration may have affected burden or depression rates for more complicated sub-groups of clients than those that were tested here. Among these may be groups with multiple chronic health conditions, or those in particular types of situational crises (e.g., hospital discharge, illness to a caregiver, acute illness episodes). Disease or event-oriented issues suggest another course for future research, again perhaps best done within integrated delivery systems.

- Finally, case management and community-based services may have a more demonstrable effect when nurses are the care managers (i.e., as in the Illinois site). One possible reason for this is that nurses may be more helpful in times of crisis or transitional health status, such as when health conditions are deteriorating or after a hospitalization.

Summary and Conclusions

The Medicare Alzheimer's Disease Demonstration was viewed by some at its initiation as a replication of the Channeling Demonstration, only targeted at the population with dementia. Like Channeling, this project employed a random assignment of applicants into treatment and control groups. Unlike Channeling this demonstration placed a primary focus on caregiver outcomes. Control group members were free to seek and use whatever community services they found helpful to them, but the enrollment process tried to minimize the number of clients who were receiving levels of care and case management at baseline that exceeded those likely to be offered by the demonstration. This criterion virtually precluded Medicaid recipients from the program, while helping to assure that baseline levels of service use and case management exposure among enrollees had room to increase through demonstration participation. The randomization process worked well at baseline and throughout the evaluation period. There is no evidence of differential attrition or retention bias between the groups over time. The program accomplished its service role reasonably well. Treatment group cases had six times the likelihood of case management exposure than controls, and an average of about a 20 percent greater likelihood of community service use. These programmatic differences did not translate into substantial treatment group reductions in

caregiver burden or depression relative to the controls. This finding is robust under a variety of analyses: all cases combined, by each demonstration model considered separately, and by consideration of each site separately. This conclusion is qualified by the limitations of the demonstration benefits and the roles played by the case managers, the intervals of data collection, and perhaps the insensitivity of the measures to nuances of burden and depression that were favorably affected.

In spite of these limitations, the consistency of these findings with those of prior case management evaluations suggests that a reformulation or extension of case manager interventions may be needed. One direction is an emphasis on support groups and peer counselling, rather than on providing services otherwise available in the community. A second direction may be to include more of an orientation to crisis intervention/resolution (beyond routine steady-state monitoring); an emphasis on expanded care (e.g., reimbursement for 24-hour in-home care) for short-term crises or transitional situations; a concerted effort to integrate case management with the client's ongoing primary care provider or as a component in chronic disease management programs. A third direction is more incremental. It would include more direct involvement of the case manager in home care worker training and supervision; and a refinement of the training given to caregivers about the disease process, service alternatives they may want to consider, and skills development in their caregiving tasks.

Many communities have explicit guidelines that preclude case manager entities from having a direct role in caregiving. This is done to help assure an objective needs assessment and to provide client advocacy. The trade-off is a possible loss in oversight of the quality of care and of changing caregiver needs. The functioning and success of private practice and managed care company case managers, who often combine these roles, is a natural laboratory for an assessment of this shift in function.

Finally, while being a family caregiver for a person with dementia can be very stressful, there are marked individual differences in the degree to which family caregivers experience these negative consequences. Typically, the research on caregiver depression and burden has focused

on the relationship between patient characteristics, behaviors, and symptoms; and that of caregiver characteristics and negative caregiver outcomes (cf., Vitaliano, et al., 1991). Many interesting issues remain to be examined, such as the adjustments made by caregivers as the disease progresses (e.g., adding formal services or passing on the primary caregiver role to more able members of the family) and the role other chronic health conditions play in the complexity of informal caregiving--and the potential benefit of case management to this role.

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Table 5-1

Baseline Variables Used as Controls for Caregiver Well-Being Outcomes[a]

Baseline Predictors	Treatment Group (n=2731) Mean	SD	Control Group (n=2576) Mean	SD
Contextual Characteristics				
Client Age	78.0	8.06	78.0	8.35
Client Gender (Male=1)	28.%		26.%	
Client Ethnicity (Minority=1)	13.%		14.%	
Caregiver Age	63.0	14.20	63.0	14.38
Caregiver Gender (Male=1)	41.%		38.%	
Client Stressors				
Client Functional Dependency[b]	-.04	1.03	-.09	1.03
• ADL Dependency[c] (0 to 10)	3.7	3.17	3.5	3.17
• IADL Impairment[d] (0 to 16)	12.8	3.60	12.6	3.65
• MMSE[e] (0 to 30)	14.9	8.63	15.2	8.57
Client Behavioral Problems[f] (0 to 19)	8.2	3.83	8.2	3.85
Hospitalized prior 6 months (Yes=1).		21.%	21.%	
Caregiver Characteristics				
Relationship				
• Spouse (Yes=1)		49.%	50.%	
• Married Child (Yes=1)		27.%	27.%	
• Unmarried Child (Yes=1)		16.%	14.%	
• Other (Yes=1)		8.%	9.%	
Caregiver Stressors				
Lives with Client		74.%	73.%	
Functional Limitations[g] (0 to 13)	1.0	2.01	1.0	1.92
Health-Fair/Poor[h] (1 to 4)	1.9	0.78	1.9	0.78
Total Hours Primary Caregiving	88.0	58.46	85.0	59.06
Number of Hours Works for Pay	12.0	18.49	12.0	18.48
Employment Limitations[j] (0 to 6).	.4	0.89	.4	0.90
Mediators				
Experimental Variables (treatment=1)				
• Model (Model B=1)				
Caregiver Income > $15,000		56.%		55.%
Client Medicaid Eligible (Yes=1)		6.%		7.%
Secondary Caregivers Assistance	2.5	3.93	2.5	3.64
Formal Providers Assistance	3.2	4.44	3.4	4.58
Receives Caregiver Services[i] (0 to 7)	0.4	0.74	0.4	0.70

[a] There were no significant differences ($p < .05$) between treatment and control groups on any baseline measure.

[b] This measure is based on summed ADL, IADL, and mental impairment scores, each standardized to have a mean of 0 and a standard deviation of 1. Higher scores indicate a higher level of functional dependency.

[c] Higher scores indicate greater ADL impairment (Katz, Ford, Moskowitz, Jackson, & Jaffee, 1963).

[d] Higher scores indicate greater IADL impairment (Lawton & Brody, 1969).

[e] Lower scores indicate greater cognitive impairment using the mini mental status examination (Folstein, Folstein & McHugh, 1975).

[f] Higher scores indicate a greater number of behavior problems (Zarit, Orr, & Zarit, 1985).

[g] Higher scores indicate greater functional limitations. [h]Higher scores indicate poorer health.

[i] Higher scores indicate a greater use of services. [j]Higher scores indicate greater employment limitations.

Table 5-2
Mean Scores on the Caregiver Well-Being Outcomes At Each Reassessment Interval[a]

Outcome Measure	Treatment Group N	Treatment Group Mean	Treatment Group SD	Control Group N	Control Group Mean	Control Group SD
Caregiver Burden[b]						
Baseline	2728	14.3	7.09	2576	14.3	7.17
6 Months	2268	14.4	7.91	2138	14.9*	8.17
12 Months	1702	14.1	8.07	1597	14.4	8.62
18 Months	1437	13.7	8.20	1283	14.3	8.62
24 Months	1528	13.8	8.20	1354	14.2	8.60
36 Months	986	13.7	8.49	920	14.2	8.73
Caregiver Depression[c]						
Baseline	2731	4.24	3.29	2576	4.21	3.28
6 Months	2269	4.29	3.42	2139	4.48	3.52
12 Months	1705	4.28	3.40	1597	4.42	3.68
18 Months	1439	4.17	3.55	1288	4.53*	3.80
24 Months	1531	4.06	3.51	1356	4.36*	3.65
36 Months	988	4.20	3.52	922	4.49	3.61

[a]Mean scores are unadjusted.

[b]Scores can range from 0 to 32. Higher scores indicate greater caregiver burden (Zarit, Reever, & Bach Peterson, 1980).

[c]Scores can range from 0 to 15. Higher scores indicate greater caregiver depression (Yesavage, Rink, Rose, & Aday, 1983).

*$p < .05$; ** $p < .01$; *** $p < .001$ difference between the treatment and control group. T-test were used to determine significant differences between the two groups.

Table 5-3

Summary of HLM Analyses of Caregiver Well-being Outcomes[a]

Outcome Measure	No. of Cases	No. of Observations	Baseline[b] Mean or Difference	Slope[c]	36 Month[d] Mean or Difference
Caregiver Burden					
1. Sample Mean	5,327	20,707	14.33	.012	14.72
2. Sample Treatment/Control Difference	5,237	20,707	- .35*	- .011	- .75
3. Model A Treatment/Control Difference	2,633	10,327	- .33	- .015	- .87
4. Model B Treatment/Control Difference	2,694	10,380	- .31	- .0003	- .32
Model A Sites:					
6. Illinois	627	2,424	- 1.11*	- .085***	- 4.17
7. New York	637	2,348	- .34	- .003	-.45
8. Oregon	692	2,866	- .58	.056*	1.44
9. Tenessee	677	2,688	.73	- .044*	-.85
Model B Sites:					
11. Florida	789	3,073	- .27	.046	1.39
12. Minnesota	888	3,316	.10	- .038***	- 1.27
13. Ohio	604	2,348	- .44	- .028	- 1.45
14. West Virginia	413	1,649	- .73	- .004	- .87
Caregiver Depression					
15. Sample Mean	5,307	20,627	4.23	.013	4.59
16. Sample Treatment/Control Difference	5,307	20,627	- .104	- .009***	- .428
17. Model A Treatment/Control Difference	2,619	10,272	- .057	- .013*	- .52
18. Model B Treatment/Control Difference	2,688	10,355	- .12	- .004	- .156
Model A Sites:					
20. Illinois	627	2424	- .47*	-.031**	- 1.59
21. New York	637	2348	- .08	-.006	- .30
22. Oregon	692	2866	- .05	.002	- .12
23. Tennessee	677	2688	.34	-.020*	- .38
Model B Sites:					
24. Florida	789	3073	.11	.012	.54
25. Minnesota	888	3316	- .19	- .006	- .41
26. Ohio	604	2348	- .13	- .025**	- 1.03
27. West Virginia	413	1649	- .35	- .016	- .93

[a] The control group is the referent group for all comparisons.

[b] If the difference is negative, then the treatment group is lower than the control group.

[c] In units per month. Treatment group is less than the control group if difference in slope is negative.

[d] Total difference between the treatment and control group at 36 months (baseline difference + 36 months x slope).

*p < .05; ** p < .01; *** p < .001.

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Chapter 6

EFFECTS OF THE DEMONSTRATION ON NURSING HOME ENTRY

BY

Robert Miller, PhD
Robert Newcomer, PhD
Ted Clay
Patrick Fox, PhD

This paper has been accepted for publication in Health Services Research, expected date of publication early 1999.

University of California, San Francisco, CA 94143

Abstract

Study Question. Did the Medicare Alzheimer's Disease Demonstration, with its goal of improving caregiver outcomes through case management and subsidized community services, affect the nursing home entry rate of treatments with dementia compared to controls?

Data Sources. Interviews were conducted at baseline and 6 months thereafter. Measures include date of nursing home entry, client and caregiver health, and income.

Study Design. The demonstration randomly assigned voluntary applicants into treatment and control groups. Treatment group cases were eligible for case management and for a 80% discount on community care benefits, up to about $600 per month.

Data Collection. All cases received baseline and semi-annual assessment interviews for up to 3 years after enrollment. Analyses are among cases that remained in the Demonstration for more than 30 days after enrollment (n=8,095).

Principal Findings. The intervention of case management and subsidized community service had no effect on nursing home entry rates for treatments overall, compared to controls, and few effects on treatment sub-groups, with the exception of one site where it may have increased nursing home entry rates.

Conclusions. Providing case-management and subsidized community services with the goal of improving caregiver outcomes may have little effect on nursing home entry rates people with dementia.

Key Words. Dementia, long term care, home care, adult day care service use, nursing home entry, institutionalization.

As consciousness of Alzheimer's disease and other dementias has increased, so have questions about how to appropriately fund and care for people with dementia. Public policy attention has focused on care for people with dementia both in nursing homes, where almost half of all patients have severe dementia (National Center for Health Statistics, 1991) and in the community. A widely cited study estimates that over 10 percent of the U.S. population age sixty-five or older had Alzheimer's disease in 1990--3.75 million cases (Bachman, Wolf, Linn et al., 1993). For persons age eighty-five or older, the estimated prevalence of severe dementia, including Alzheimer's disease, is much higher, ranging from 25 to 45 percent of those living in the community. Almost two-thirds of those with dementia are thought to have Alzheimer's disease. Alzheimer's disease is characterized by progressive disorientation to time, place, and person; deterioration of personality; and physical incapacitation.

The Health Care Financing Administration implemented the Medicare Alzheimer's Disease Demonstration and Evaluation (MADDE) program [1] in order to explore one approach to serving the needs of two groups: caregivers for people with dementia and people with dementia themselves. The primary program goal was to improve the well-being of caregivers of people with dementia through case-management and Medicare-subsidized community support services (including home care, companion care, and adult day care). Caregiver health-related outcomes measures included depression, stress, and burden. The evaluation also determined the effect of the intervention on program client (treatment) health outcomes (including physical functioning, behavior, cognitive functioning, and mortality) and on client utilization outcomes (including use of nursing home, community, hospital and physician services.

The Demonstration did not have an explicit goal of reducing nursing home use, unlike many other demonstrations. Thus, the demonstration provided the opportunity to determine how nursing home use was affected by interventions designed to improve caregiver outcomes. This

[1] This demonstration was authorized by section 9342 of the Omnibus Budget Reconciliation Act of 1986 (OBRA-86) and funded under Health Care Financing Administration contract 500-89-0069

focus on caregiver outcomes created the possibility that the intervention actually could increase nursing home use, rather than reduce it or have no effect.

The Demonstration consisted of two program models, with four sites assigned to each model. The models varied on the ratio of treatments to case managers, and the amount of Medicare coverage available each month for treatment benefits. MADDE randomly assigned participants who were demented and their caregivers to treatment and control status.

MADDEfocused solely on cognitively impaired persons and their caregivers. Enrolling only people with dementia allowed MADDE case managers to become experts in the particular problems faced by caregivers of people with dementia, and in the community care available to them.

This paper assesses whether the MADDE intervention changed nursing home entry rates for treatments, compared to controls. Previous evaluations of community-based service demonstrations that included mixed groups of people with and without dementia and whose goal was to reduce nursing home use concluded that case management and subsidized home and community-based services did little to change nursing home entry rates for program clients, compared to controls or comparisons (Kemper, Applebaum & Harrigan, 1987; Weissert, Cready & Pawelak, 1988). For example, the Channeling Demonstration Evaluation found no effect on nursing home entry rates for treatments, including subgroups categorized as having severe, moderate and mild/no cognitive impairment (Wooldridge & Schore, 1988). Until MADDE, it has remained unclear whether a large community service oriented intervention focused exclusively on people with dementia and whose goal was to improve outcomes of caregivers would affect nursing home use by people with dementia.

Demonstration Design

The demonstration enrolled participants that met four criteria: (1) Diagnosis of irreversible dementia; (2) Enrollment in Parts A and B of the Medicare program; (3) Residence in a Demonstration site's catchment area; (4) Living in the community at the time of their application to the program. Enrollment into the demonstration occurred between December 1989 and November

30, 1991. Eligible applicants were randomly assigned into treatment and control status after their initial screening interview.

MADDE site programs could provide case management and subsidized community services to the program clients for up to three years, if the client remained living in the community. Clients were disenrolled from the program 60 days following a nursing home placement, and continued to be tracked for up to one year after placement.

Model B programs (Cincinnati, OH; Parkersburg, WV; Minneapolis, MN; and Miami, FL) provided program clients with somewhat fuller benefits coverage than did Model A programs (Rochester, NY; Urbana, IL; Memphis, TN; and Portland, OR). Both Models covered the same set of services, but Model B had richer benefits. Whereas Model B programs had a case manager to client target ratio of 1:30, Model A programs had a 1:100 target ratio. Moreover, whereas Model B client/caregivers could use a $430-$699 maximum benefit per client per month for demonstration services, Model A client/caregivers could use a $290-$489 maximum benefit per client per month.[2] Client caregivers could purchase a wide array of demonstration-subsidized services, including homemaker/chore, personal care, companion services, social or dementia-specific adult day care, and other community services. In both Models, program clients paid 20 percent of the price (i.e., a 20 percent coinsurance rate) for demonstration-subsidized services.

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[2] Reimbursement caps in each model varied by site over time due to regional cost variations and inflation adjustments. Acute care and other skilled care services usually covered under Medicare continued to be reimbursed as part of the regular Medicare benefit. Medicaid recipients in all study communities had access to benefits that exceed those of the Medicare waiver. For this reason, sites were limited in the proportion of Medicaid recipients who could enroll in the demonstration. All but one site chose to exclude Medicaid recipients. Participants could remain in the demonstration if they became Medicaid eligible after baseline.

More than 90 percent of the treatment group (in both models) used case management services, a rate six times that of the control group. Differentials between groups in the rate of use of personal services were substantially less. About half of the treatment group in each Model used paid personal services at some point during their demonstration enrollment, compared to 40 percent of controls. About 29 percent of Model A and 45 percent of Model B program clients used day care, compared to 25 percent of controls. Between treatments and controls, statistically significant differences in the likelihood of personal care service use were observed in Oregon and Tennessee (Model A sites), and Florida and Minnesota (Model B sites). Significant differences in the likelihood of day care service use were observed in all but Oregon. In general, the likelihood of use of homemaker/chore service, personal care, and day care increased for participants in both groups with their length of time in the Demonstration, and in the months preceding nursing home placement (See Chapter 4 of this report).

Case management services were provided without charge. Details on the range of subsidized services used by treatment and control group members within each of the program sites, and other Demonstration characteristics are discussed in Chapter 4 of this report.

The eight sites differed in important ways, including in their long-term care service environment characteristics, urban/rural and race/ethnicity composition, and content of the intervention (U.S. Department of Health and Human Services, 1992). For example, sites in New York, Oregon, Florida, and Ohio operated in well-developed home and community-based services program environments, whereas sites in Illinois, West Virginia, and the rural areas of Tennessee and Minnesota did not. One site (Minneapolis) had over twice the number of nursing home beds per thousand persons 75 and over than did another (Memphis, TN). Although all sponsoring agencies were located in cities, urban/rural composition varied because four sites included rural counties in their catchment area. Race and ethnicity composition also varied substantially among sites. "Non-Hispanic whites" accounted for about 95 percent of participants in five sites, but African-Americans accounted for one-third of participants in Tennessee and 15 percent of participants in Ohio. Hispanic whites accounted for one-fifth of participants in Miami, FL.

Each site agency implemented the demonstration in somewhat different ways. For example, the Illinois program employed nurses as case-managers, whereas other Model A sites and all the Model B sites employed social workers as case managers. Overall, site agencies made little attempt to integrate long-term care (formal and informal) services with medical services. Only in Illinois did nurse case-managers attempt to intervene specifically to alter the pattern of medical care. Organizational arrangements among site agencies also varied widely. Some agencies provided services through their own home care departments whereas others contracted out for services. As a result, formal caregiver education also varied: although case-managers were supposed to train agency staff, their training activities varied when agencies contracted out.

Hypotheses

Because the Demonstration intervention was designed to improve caregiver well-being, there was no *a priori* assumption about the Demonstration's effect on nursing home entry rates. Three competing hypotheses were considered in testing the MADDE intervention effect on the nursing home entry rates of treatment group members.

Hypothesis #1: Slower rate of entry into nursing homes could occur if Demonstration interventions of case management and increased use of community services (due to the 80 percent price discount), may have provided enough added supports to enable treatment group community caregiving for a longer time, compared to control group caregiving.

Hypothesis #2: Faster rate of entry into nursing homes could occur (and be desirable) if case managers, in acting as caregiver advocates, helped client caregivers to acknowledge the necessity to "let go" and institutionalize people with dementia needing placement, or if case-managers used their influence within the community to arrange quicker placement of a person needing nursing home care.

Hypothesis #3: No change in the nursing home entry rate may occur if the Demonstration interventions had no effect, or if some interventions increased, and other interventions decreased, the rate of nursing home entry for sub-groups of treatments. Demonstration guidelines did not require case managers to encourage caregivers to delay institutionalization of people with dementia.

Methods

Of the 8,387 applicants that qualified for inclusion, these analyses use data on 8,095 applicants (96.4% of the total) who remained in the demonstration for at least 30 days, including 3,944 controls and 4,151 program clients. During the first month, 97 participants died, 160 entered a nursing home, and 35 dropped out. These cases were excluded under the assumption that the program did not have sufficient opportunity to have an impact on the needs of the caregivers during such a short interval. There were no statistically significant differences in the proportion of treatments and controls in any of those 3 categories.

Client and caregiver functional health status, psychological status, and other attributes were collected at baseline, and every 6 months for up to 3 years in the community, or for up to one year after nursing home entry. Participant retention was relatively high, as only 811 participants were lost to follow-up, with no difference in the lost to follow up rate between treatments (8.1%)

and controls (8.6%).[3] Lost-to-follow-up participants were slightly younger, had modestly less income and dementia, and higher functioning compared to those that remained in the study. Compared to controls, treatment subjects that dropped out had fewer unmet needs at baseline, and somewhat higher functioning in activities of daily living (ADL) (2.8 v 3.7 limitations) and instrumental activities of daily living (IADL) (5.8 v 6.3 limitations), and less dementia. Covariates were used in the analyses to control for effects of attrition biases.

We evaluated "permanent" or "one-way" nursing home entries, which were defined as stays that did not lead to live discharge to the community (ie, stays that ended in death or that continued beyond the point when data collection stopped). Short stays of participants that returned to the community were excluded under the assumption that these stays were mostly likely due to an episodic acute care event, rather than to dementia or other long-term, chronic conditions. The remaining short-stay nursing home entries accounted for less than 5.4% of all nursing home days (5.3% for treatments and 5.4% for controls).

Demented participants had a relatively high rate of permanent nursing home entry. Of the original group of 8,095 participants, 43.5% had a permanent nursing home stay during the 3 year period (44.1% for treatments and 42.9% for controls). On average, participants spent over 18% of total days (or "exposure days") in the demonstration in permanent nursing home stays. As a percent of total exposure days, there were no statistically significant differences between treatments (18.4%) and controls (18.9%) in such use.

The Evaluation obtained nursing home entry dates for any stays that: the caregiver thought were permanent; the case-manager expected to be permanent (for treatment group members only); lasted more than 60 days; and were paid for by Medicare and that ended in death. It did not obtain nursing home entry dates for some short-stays that were not expected to be permanent, although it did obtain number of nursing home days.

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[3] The 811 cases remained in the Cox proportional hazards model as right-censored cases--that is, they were retained in the model to the point of being lost to follow-up.

Data quality was comparable between treatments and controls for long-stays greater than 60 days. The Evaluation put much effort and resources into obtaining information from caregivers over time, as indicated by the high participant retention rate and accompanying high caregiver interview response rate. It was highly unlikely that either a treatment or control caregiver would not report a stay of 61 or more days (and thus be queried for an entry date for those stays). Analyses among the treatment group members that compared self reported service use with demonstration-financed service claims records found that caregivers correctly identified the receipt of demonstration-financed services in a high proportion of cases (Donatoni, 1997). Given the importance of nursing home entry as a major event in the lives of people with dementia and their caregivers, it is reasonable to expect that a similarly high a rate of correct reporting occurred for nursing home entries as well, especially those of substantial duration. To the extent that there was bias for finding more long-term one-way nursing home entries among treatments than controls because of additional case-manager information, that bias likely was slight.

The Evaluation was somewhat more likely to obtain entry dates for treatment nursing home residents that died within 61 days of nursing home entry than for controls,[4] which would bias

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[4] From both treatment and control caregivers, the Evaluation obtained nursing home entry dates for persons that had nursing home stays of 61 days or more, or for persons that had shorter stays, were still alive, and had been identified by caregivers as having had a permanent nursing home entry. For persons that had shorter stays and had died by the time of the interview, caregivers were not asked whether or not the person died in the nursing home or for an entry date, so that the Evaluation was unclear about whether such persons had died in a nursing home. However, the Evaluation did know from caregivers that there had been a nursing home stay in the previous six month period, the number of days of the stay, and that the participant had died. The Evaluation would have information on some treatments in that sub-group, if case-managers had identified those treatments as having entered a nursing home on a permanent basis, in which case an entry date was obtained. Of course, case-managers could not similarly identify controls, which created the bias.

As a result, of the 256 participants that had been designated as having had a permanent entry and that died in a nursing home within 60 days of entry, 89 were controls while 167 were treatments. In contrast, of the 150 participants whose caregivers had reported a nursing home stay of under 61 days, were not identified as having had a permanent entry by either caregivers or case-managers, and that died in the same period, 100 were controls while 50 were treatments. In comparison to both, for the 80 people with dementia that died in a Medicare-paid nursing home stay within 61 days of entry (according to Medicare Part A data), the numbers of treatments and controls were equal. Similarly, for the 1500 people with dementia that entered a nursing home and were alive 61 days later, the numbers of treatments and controls were equal.

Another source of bias might be due to caregivers not reporting short nursing home stays when they occurred. While possible, it would have to have occurred on an improbably massive scale to affect results in the proportional hazards model.

results against finding that the Demonstration reduced nursing home entry rates for treatments. In particular, it was unclear whether or not 150 short-stay people with dementia, many of them controls, had died in a nursing home and thus should be considered as having had a permanent nursing home entry.[5] To compensate for potential bias, we conducted one analysis that assumed that the 150 had died in a nursing home (thereby increasing the number of permanent stays by about 4.5%), another that assumed the 150 had died in the community, and a third that defined a permanent nursing home stay as one that lasted 61 days or longer. In all cases, results were similar to those reported here.

Participants also had high mortality rates. Of the analysis group of 8,095 participants with dementia, 34.5% of controls and 35.1% of treatments died before the end of three years in the project.[6]

The participant sample consisted primarily of non-Hispanic whites (87.3 percent of the sample) that were predominantly women (61.3 percent), and older (average age, 78.9 years). Treatment and control participant characteristics were very similar, and any the few statistically significant differences in characteristics were small. Table 6-1 compares treatment and control group characteristics.

Insert Table 6-1 About Here

Although randomization produced comparable groups of treatments and controls at baseline, we used covariates in the analysis in order to increase the precision of the estimates of the effect of the demonstration on nursing home entry (by reducing unexplained variance in the outcome variable) and to help control for informative censoring that took place between death (a censoring event) and nursing home entry. Informative censoring can occur when censoring is non-random--that is, when those that died are a biased sub-sample of the participants at risk of a

[5] The 150 short-stay participants entered a nursing home at some point during a six-month period, stayed less than 61 days, died during the same period, and had not been designated as having had a permanent entry (see the previous note).

[6] However, the actual mortality rate was higher than that during that 3 year period, since the Evaluation could not follow for the entire 3 years the 8.6% of controls and 8.1% of treatments that dropped out of the study or the 18.8% of controls and 18.4% of treatments that were no longer followed after staying in a nursing home for one year.

nursing home event. Because the most effective means for controlling for informative censoring is to include as many covariates as possible that could affect the dependent variable (Allison, 1995), several other nursing home entry analyses using survival analysis models adopted this approach to address the same issue (Garber & McCurdy, 1989; Greene & Ondrich, 1990; Headen, 1991). Note that in the present analysis there was no difference in mortality rates for treatments compared to controls, in either the univariate or multivariate analyses, and therefore no bias was introduced due to differences in censoring due to death (or other attrition).

In addition to site, multivariate models included covariates selected to adjust for client and caregiver predisposing, enabling, and various presumptive service need attributes.

1. Client health variables included:

- dependence on personal assistance in IADL tasks (meal preparation, shopping, routine housework, managing money, laundry, telephone, medications, heavy chores/maintenance) (Lawton & Brody, 1969);

- dependence on personal assistance in ADL tasks (walking, wheeling, transfers from bed/chair, grooming, bathing, dressing, eating, using the toilet, and bowel/bladder accidents) (Katz, Ford, Moskowitz et al., 1963);

- client behavior problems (up to 19), such as asking repetitive questions, being suspicious or accusative, having trouble recognizing familiar people, engaging in behavior potentially dangerous to self or others (Zarit, Orr & Zarit, 1985);

- client dementia as measured by the Mini-Mental Status Exam (MMSE) (Folstein, Folstein & McHugh, 1975), which includes items pertaining to orientation, recall, and naming objects.

2. Client demographic variables included race, age, income, supplementary Medicare insurance status, and type of home ownership.

3. Caregiver health, functioning, and service need variables included: caregiver burden as measured by the Zarit Burden Scale (Zarit, Reever & Bach-Peterson, 1980; Zarit, Todd & Zarit, 1986) which includes 7 items; depression as measured by the Geriatric Depression Scale (Yesavage, Brink, Rose et al., 1983) which includes 15 items; family-related stress (the Zarit Stress Scale) (Zarit, Orr & Zarit, 1985); and caregiver service unmet need (not enough help) for ADLs with limitations.

4. Caregiver demographics included caregiver relationship to client, age, income, education, HMO membership, and Medicaid status.

In the multivariate model, we included all potential variables that made a statistically significant contribution to reducing unexplained variance in the dependent variable. We omitted caregiver gender, given its collinearity with type of caregiver.

Time-dependent covariates were used for client health/functioning characteristics, with the exception of the MMSE covariate which was measured at baseline only. Baseline data were used for several caregiver health/functioning characteristics because other analyses showed that the intervention may have decreased caregiver depression, burden, and unmet service needs over time[7] (Newcomer, Yordi, Dunah et al., 1998; Yordi, DuNah, Fox et al., 1998). For all health/functioning variables, there was little difference in estimates of the effect of the Demonstration on nursing home entry rates when we used covariates with time dependent values, covariates with base-line values, or a mix of the two.

For continuous variables, missing data was imputed by inserting average values for observations with data. For each categorical variable with missing data, a dummy variable representing observations with missing data was inserted into the regression analysis.
A Cox proportional hazards regression model was used to estimate the Demonstration effects on the rate of nursing home entry. Compared to a linear regression model with only baseline variables, the proportional hazards model has two advantages. It corrects for bias in estimates in ordinary least squares models caused by censoring, and it can use data from surveys subsequent to the baseline period. Moreover, the semi-parametric Cox proportional hazards model does not require specification of the hazard function shape, which is useful when there are no prior assumptions about that shape.

The Cox proportional hazards model proportionality assumption was met, as indicated by visual inspection of the log-log nursing home functions for the covariates, for almost all variables

[7] This was suggested by comparing treatment and control group means for variables measured after baseline (controlling for baseline values). Although most treatment effects on these attributes were weak in any one period (e.g., the difference in caregiver ADL at 18 months was not statistically significant) significant differences between the two groups emerged when means of the mean difference from baseline for all periods for each individual were computed. For example, if a client had scores from six post-baseline interviews, the mean score of the difference

when expressed as categorical variables. Even in cases where the proportionality assumption is not met, the estimation method remains fairly robust (Allison, 1995). For the Cox model, a covariate hazard ratio of greater than one (1) indicates a higher nursing home entry rate for treatment group cases compared to those in the control group. A hazard ratio less than one (1) indicates a lower nursing home entry rate.

A Weibull (parametric) distribution model also was used to test the effect of the intervention. As there were no substantial differences in results produced by any of the semi-parametric and parametric models, only the Cox proportional hazards model results are reported. Because the nursing home entry rate was flat over time, a parametric exponential model was used to estimate differences in median and mean time to nursing home entry between the two groups.[8]

We put substantial effort into determining whether the Demonstration interventions had positive or negative effects on rates of nursing home entry for different sub-groups of treatments. We paid particular attention to possible differences in Demonstration effects by caregiver type because several studies showed that disabled elderly without spouses were more likely to enter nursing homes than those with spouses (see (Hanley, Alecxih, Wiener et al., 1990) for a review of research in this area), whereas another study showed that nursing home entry rates differed for elders whose caregivers were spouses rather than adult children (Montgomery & Kosloski, 1994).

Potential intervention effects on sub-groups were tested for statistical significance using interaction terms for the covariates and the treatment group indicator variable. Covariates were tested for the statistical significance of a block of interaction terms at a time (for categorical variables). Model, site, and type of caregiver intervention effects also were tested using separate sub-samples. For example, we estimated coefficients using the Model A and Model B samples separately. Although including interaction terms for some variables in a multiple regression model permits use of the full sample, using sub-samples to determine sub-group effects permits values of all coefficients of covariates to vary for each sub-group, not just covariates with interaction terms.

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between each interview score and baseline was computed, and the resulting values were then compared between clients and controls.

Results

Compared to controls, Demonstration interventions did not change treatment nursing home entry rates, for all sites combined, or for each Model. Except for the apparent effect of the Demonstration in increasing client nursing home entry rates in Rochester, NY, the interventions appeared to have no effect in changing client nursing home entry rates for the other seven sites, or for other sub-groups.

1. Intervention effect, for all sites combined. For all sites combined, the Demonstration interventions had no apparent effect on nursing home entry rates for program clients compared to controls, in either the univariate or multivariate analyses. Treatments/controls relative hazard ratios were statistically insignificant in the univariate (hazard ratio = 1.01, p-value = .776) and multivariate (hazard ratio=1.01, p-value = .877) analysis models. The negligible difference in hazard ratios between the univariate and multivariate models reflected the success of randomization efforts.

   Insert Table 6-2 About Here

   When we used a parametric exponential form of the Weibull model to estimate time to nursing home entry, we obtained similar, non-significant results for the treatment indicator. The median estimated time to nursing home entry was 1011 days for treatments, compared to 1023 for controls.

2. Intervention effect, for Model A and Model B separately. Compared to controls, there was no effect on the nursing home placement likelihood for Model A program clients (hazard ratio=1.07, p-value=.149) or Model B program clients (hazard ratio=.96, p-value = .410).

   Insert Table 6-3 About Here

3. Intervention effect, for each site separately. In seven of eight sites, the Demonstration intervention had no apparent effect on client nursing home entry rates. However, in Rochester, NY, the Demonstration intervention appeared to increase the likelihood of nursing home placement, compared to controls (hazard ratio=1.21, p-value=.043).

   Insert Table 6-4 About Here

4. Intervention effect, for sub-groups. In the multivariate models with the full sample, the Demonstration had no effect in changing nursing home rates for sub-groups of program clients and their caregivers. None of the many treatment/covariate interaction terms, or blocks of interaction terms (for categorical covariates), significantly decreased model variance. As well, there were no statistically significant intervention effects when we estimated the Demonstration effect for each major type of caregiver separately.

   Insert Table 6-5 About Here

5. Other tests of the intervention effect. No treatment effect was found when baseline data was substituted for continuous time covariates (hazard ratio=1.00, p-value=.956), suggesting that

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[8] For computational purposes, the date of nursing home entry was rounded to the nearest month in all analyses.

using continuous-time independent variables had little effect on results. There also was no treatment effect (hazard ratio=1.00, p=0.995) found using the exponential form of the Weibull model.

Discussion

Given its aim to improve outcomes for caregivers of people with dementia, it was possible to hypothesize that Demonstration might decrease, increase or have no effect on treatment nursing home entry rates. Overall, it appeared that the Demonstration had little effect on nursing home entry rates for all treatments combined (potentially confirming Hypothesis #3 above), or for sub-groups of treatments.

The Demonstration intervention had only one potentially significant effect on nursing home entry rates for a treatment sub-group. In Rochester, NY, program clients may have had a higher nursing home entry rate than did controls (potentially confirming Hypothesis #2 above). Results similar to those in Rochester were not found for the other three Model A program sites.

There are several possible explanations for the Rochester NY results. "False positive" and "false negative" results were likely to occur in the analyses, given that we tested for the statistical significance of the intervention effect on many sub-groups. Moreover, because the p-value of .043 for the treatment variable coefficient was just under the cutoff .05 significance level value, a small change in the definition of nursing home entry could alter the statistical significance of the results. For example, when people that stayed in a nursing home for more than 60 days were considered as nursing home entrants, the p-value of the treatment variable coefficient was .0502, or slightly more than the cutoff .05 significance level value.

Other explanations also are possible. Because the primary goal of the Demonstration was to reduce caregiver stress and burden, not nursing home utilization, case managers were less constrained in the case-management help that they could provide to caregivers deciding whether or not to institutionalize their relative who was demented. In many other Demonstrations, case managers were under some organizational pressure to reduce institutionalization. As hypothesized above, without that pressure in this Demonstration, case managers acting as caregiver advocates may have helped treatment caregivers to "let go" and institutionalize the person with dementia. . A

follow-up survey with families placing members in nursing homes was conducted in all sites (Elliot & Corona, 1996). There is little evidence from family members to explain why the Demonstration may have had an effect on placement rates in Rochester and not others. If there was an effect—and the data only suggests that there may have been one--the explanation seems to lie with the case manager's practices. That is, the Rochester, NY Demonstration case managers simply may have had a stronger propensity to recommend nursing home placement than in other sites. However, why these practices would differ is unclear, given available evidence.

Still, the overall thrust of the results suggests that the MADDE intervention had little impact on changing nursing home entry rates. This is consistent with evidence from evaluations of other home and community-based interventions for mixed groups of cognitively impaired and intact participants that had as their goal reducing nursing home use.

Several alternative theories have been offered to explain past results, such as failure of Demonstrations to carefully target and allocate services to users that might be helped (Weissert & Cready, 1989; Weissert, Cready & Pawelak, 1988) and be system-changing (ie, affect an entire community long-term care service supply system, including prices and types and quality of services offered) (Kane, 1988), as well as failure to sufficiently restructure and realign incentives and practices, including those on the acute care side. However, the Demonstration could not shed any light on these issues, given that past explanations pertained to Demonstrations that specifically attempted to lower nursing home use, whereas this Demonstration did not.

Several potential Demonstration limitations may have reduced the effect (positive or negative) of the Demonstration on nursing home entry rates.

- Demonstration agencies may not have generated enough additional demand for community services to have had an effect on nursing home use. The demonstration program did stimulate additional demand for community services--treatment group members were at least 20 percent more likely to use these services than were control group members--and the likelihood of treatment service use increased over time. Nevertheless, a substantial minority of caregivers either never initiated services or else discontinued service use during the three year tracking period, due to a variety of factors. Not perceiving a need or benefit from the assistance was the most frequently mentioned explanation by caregivers, and cost of services was also mentioned. Many potential users did not see sufficient value from the services (relative to other goods and services) to purchase them, even given the 80 percent discount.

- The relatively small effect on the rate of community service use was at least partly due to the benefit cap, which may have been too low to have an effect on changing community service use and institutionalization rates. However, the Channeling Demonstration maximum benefit was set at 60 percent of the monthly cost of a nursing home stay--substantially in excess of the MADDE maximum benefit. Even with substantially higher coverage for community care, that demonstration also failed to affect nursing home placement rates.

- Demonstration agencies could not integrate acute and long term care service processes or financial incentives (including joint capitation for services). As a result, they had no control over medical interventions that may have prevented acute episodes that might have led to institutionalization.

- Demonstration funded services did not substantially differ from the types of services already available to others in the community (including those in the control group). It is unknown if results would have been different if the demonstration been more able to affect home care aide training, or had made available home care services 24-hours a day, seven days a week.

Although the results that show no Demonstration intervention effect on treatment group nursing home entry rates appear to be robust, it remains possible that the intervention may have affected nursing home entry rates of more complicated sub-groups of program clients than those compared here. However, because the list of possible combinations of characteristics and sub-groups is great, the likelihood of finding false "positives"--finding an effect where none exists--rises as comparisons rise.

Summary and Conclusion

The MADDE attempted to improve the lives of persons with dementia and their caregivers. Given the large number of persons randomly assigned into treatment and control groups, it was possible to determine whether MADDE had any effect on program clients and their caregiver outcomes, including nursing home use.

This evaluation indicates that the Demonstration had little effect on treatment nursing home entry rates, compared to controls. The question that MADDE did not answer is whether substantially more innovative medical and social services incentives and practices might have changed client nursing home entry rates. For example, in the acute care sector, a fundamental shift in Medicare payment incentives to providers, from fee-for-service to capitation, has led to dramatic decreases in hospital days per thousand Medicare enrollees (Robinson & Casalino, 1995). Yet for

years, prior to these major changes, many argued that that there were few acute care savings possible in the health system (Schwartz & Mendelson, 1994).

Similarly, some might argue that only radical changes in long-term care service organization, practice, incentives, and integration with acute care, might affect nursing home rates. Given that there were no such fundamental shifts in provider incentives or organization in MADDE, many questions remain unanswered about what constitutes optimal community-oriented interventions aimed at people with dementia and their caregivers. At the same time, it can be concluded that the provision of case management and community services within the ranges available from this demonstration was not sufficient to change the rate of nursing home entry.

Table 6-1: Descriptive statistics for treatments and controls at baseline

	Dummy	Treatments		Controls			Dummy	Treatments		Controls	
Variable	Variable	N	Pct	N	Pct	Variable	Variable	N	Pct	N	Pct
Site	FL	593	14.3	564	14.3	CL race	black	342	8.2	358	9.1
	IL	515	12.4	484	12.3		hispanic white	146	3.5	134	3.4
	OR	485	11.7	447	11.3		race other	23	0.6	22	0.6
	MN	738	17.8	679	17.2		white	3640	87.7	3430	87.0
	NY	530	12.8	518	13.1						
	OH	481	11.6	446	11.3	CL age	20 to 64	138	3.3	148	3.8
	TN	499	12.0	487	12.3		65 to 69	355	8.6	319	8.1
	WV	310	7.5	319	8.1		70 to 79	1756	42.3	1624	41.2
							80 to 85	1010	24.3	973	24.7
MMSE	0	390	9.4	359	9.1		85 to 90	640	15.4	647	16.4
score	1 to 5	353	8.5	326	8.3		90 plus	252	6.1	233	5.9
	6 to 10	408	9.8	421	10.7						
	11 to 15	654	15.8	641	16.3	CL	yes	275	6.6	271	6.9
	16 to 20	890	21.4	831	21.1	Medicaid	no	3876	93.4	3673	93.1
	21 to 25	826	19.9	734	18.6						
	26 to 30	382	9.2	394	10.0	CL income	under $5k	311	7.5	269	6.8
	missing	248	6.0	238	6.0		5,000-9,999	1070	25.8	1066	27.0
							10,000-19,999	1476	35.6	1408	35.7
IADL	0-3	297	7.2	267	6.8		20,000-29,999	633	15.2	577	14.6
limitations	3.5 to 5.5	805	19.4	823	20.9		30,000 & over	482	11.6	449	11.4
	6 to 6.5	655	15.8	596	15.1		missing	179	4.3	175	4.4
	7 to 7.5	1121	27.0	1073	27.2						
	8	1273	30.7	1184	30.0	CL owns	rents	735	17.7	715	18.1
	missing	0	0.0	1	0.0	or rents	free w/ relative	1413	34.0	1364	34.6
							owns	2003	48.3	1865	47.3
ADL	0 to 1	845	20.4	812	20.6						
limitations	1.5 to 2	680	16.4	659	16.7	CL	male	1608	38.7	1611	40.8
	2.5 to 3	586	14.1	553	14.0	gender*	female	2543	61.3	2333	59.2
	3.5 to 5	915	22.0	804	20.4						
	5.5 to 8	669	16.1	655	16.6	CL	elementary	1072	25.8	1045	26.5
	8.5 to 10	456	11.0	460	11.7	education*	some hs	757	18.2	734	18.6
	missing	0	0.0	1	0.0		hs graduate	1131	27.2	1133	28.7
							some college	584	14.1	535	13.6
Behavior	0 to 4	625	15.1	559	14.2		coll graduate	579	13.9	483	12.2
problems	5 to 7	910	21.9	848	21.5		missing	28	0.7	14	0.4
	8 to 10	1019	24.5	1016	25.8						
	11 to 13	954	23.0	859	21.8	CL HMO	Yes	916	22.1	792	20.1
	14 to 19	625	15.1	650	16.5	member**	No	3235	77.9	3152	79.9
	missing	18	0.4	12	0.3						
						Lives with	Yes	2916	70.2	2769	70.2
Self-rated	excellent	1173	28.3	1128	28.6	caregiver	No	1235	29.8	1175	29.8
health	good	1946	46.9	1804	45.7						
	fair	777	18.7	754	19.1						
	poor	143	3.4	161	4.1						
	missing	112	2.7	97	2.5						

Table 6-1: Descriptive statistics (continued)

Variable	Dummy Variable	Treatments N	Treatments Pct	Controls N	Controls Pct	Variable	Dummy Variable	Treatments N	Treatments Pct	Controls N	Controls Pct
Stress in family	never	704	17.0	599	15.2	CG IADL limitations	4 to 8	405	9.8	412	10.4
	rarely	269	6.5	284	7.2		missing	118	2.8	104	2.6
	sometimes	1338	32.2	1303	33.0						
	frequently	938	22.6	916	23.2	CG relation	husband	700	16.9	621	15.7
	always	624	15.0	602	15.3		wife	1247	30.0	1211	30.7
	missing	278	6.7	240	6.1		daughter	1194	28.8	1087	27.6
							daught-in-law	148	3.6	153	3.9
CG ADL limitations *	0	3434	82.7	3236	82.0		son	336	8.1	330	8.4
	1	362	8.7	404	10.2		female relative	246	5.9	272	6.9
	2 to 5	239	5.8	204	5.2		other	261	6.3	237	6.0
	missing	116	2.8	100	2.5		missing	19	0.5	33	0.8
Employ-ment limitations	yes	785	18.9	741	18.8	CG age	under 70	2413	58.1	2341	59.4
	no	553	13.3	549	13.9		70 to 74	524	12.6	477	12.1
	missing	2813	67.8	2654	67.3		75 to 79	527	12.7	469	11.9
							80 to 84	342	8.2	337	8.5
Stress in work	never	145	3.5	177	4.5		85 plus	161	3.9	165	4.2
	rarely	139	3.3	137	3.5		missing	184	4.4	155	3.9
	sometimes	511	12.3	479	12.1						
	frequently	313	7.5	294	7.5	CG income	under 10,000	313	7.5	328	8.3
	always	211	5.1	183	4.6		10,000-40,000	1008	24.3	924	23.4
	missing	19	0.5	20	0.5		40,000 & over	576	13.9	574	14.6
	does not work	2813	67.8	2654	67.3		missing	2254	54.3	2118	53.7
Unmet needs	None	672	16.2	653	16.6	CG education	less than hs	855	20.6	789	20.0
	.5 to 1	269	6.5	259	6.6		hs graduate	1258	30.3	1188	30.1
	1.5 to 2.5	224	5.4	219	5.6		some college	989	23.8	966	24.5
	3 to 5	334	8.0	271	6.9		coll graduate	932	22.5	903	22.9
	5.5 to 18	444	10.7	442	11.2		missing	117	2.8	98	2.5
	missing	2208	53.2	2100	53.2						
						CG Medicaid	Yes	99	2.4	109	2.8
CG depression scale	0	341	8.2	321	8.1		No	4052	97.6	3835	97.2
	1 to 2	1099	26.5	1042	26.4						
	3 to 4	944	22.7	905	22.9	CG Medicare	Yes	2022	48.7	1896	48.1
	5 to 6	660	15.9	648	16.4		No	2129	51.3	2048	51.9
	7 to 8	447	10.8	418	10.6						
	9 to 15	539	13.0	498	12.6	CG Medi-gap	Yes	811	19.5	761	19.3
	missing	121	2.9	112	2.8		No	3340	80.5	3183	80.7
CG IADL limitations	0	2835	68.3	2698	68.4	CG retirement health plan	Yes	618	14.9	580	14.7
	1	375	9.0	339	8.6		No	3533	85.1	3364	85.3
	2 to 3	418	10.1	391	9.9						

CL=client; CG=caregiver; hs=high school; daught=daughter; *, ** Differences between treatment and control groups are statistically significant at the .10 and.05 levels respectively

Table 6-2

Treatment Effect on Home Entry Rates, All Sites Combined, Clients v Controls

Model	N	Relative hazard ratio T v C	Lower 95% hazard ratio CI	Upper 95% hazard ratio CI	P-value
Univariate	8095	1.010	.945	1.079	.776
Multivariate	8095	1.005	.941	1.074	.877

Table 6-3

Treatment Effect on Nursing Home Entry Rates, Model A and B Sites Separately, Clients v controls, Multivariate Analyses

Sample	N	Relative hazard ratio T v C	Lower 95% hazard ratio CI	Upper 95% hazard ratio CI	P-value
Model A sites	3965	1.075	0.975	1.185	0.1487
Model B sites	4130	0.962	0.878	1.055	0.4097

Table 6-4

Treatment Effect on Nursing Home Entry Rates, Each Site Separately, Clients v Controls, Multivariate Analyses

Sites	N	Relative hazard ratio T v C	Lower 95% hazard ratio CI	Upper 95% hazard ratio CI	P-value
MODEL A					
Urbana, IL	999	1.046	.873	1.253	.626
Rochester, NY	1048	1.213	1.006	1.463	.043
Portland, OR	932	.948	.746	1.203	.660
Parkersburg, WV	629	.812	.620	1.064	.131
MODEL B					
Miami, FL	1157	.856	.681	1.076	.182
Minneapolis, MN	1417	1.010	.877	1.164	.888
Cincinnati, OH	927	.941	.776	1.140	.533
Memphis, TN	986	.902	.719	1.132	.374

Table 6-5

Treatment Effect on Nursing Home Entry Rates, various subgroup samples, Clients v Controls, Multivariate Analyses

Caregiver Types	N	Relative hazard ratio T v C	Lower 95% hazard ratio CI	Upper 95% hazard ratio CI	P-value
Husbands	1321	0.93	0.788	1.098	0.394
Wives	2458	1.045	0.926	1.179	0.476
Son	666	0.983	0.772	1.251	0.886
Daughters	2281	1.019	0.892	1.164	0.781
Daughter-in-law	301	1.216	0.833	1.777	0.311

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Chapter 7

Effects of the Demonstration on Medicare Expenditures

by

Robert Newcomer, PhD[1]
Robert Miller, PhD[1]
Ted Clay, MS[2]
Patrick Fox, PhD[1]

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[1]University of California, San Francisco
[2]Clay Software and Statistics, Ashland, Oregon

Abstract

Applicants were randomized either into a treatment group having access to a limited Medicare community care service benefit and case management or into a control group that received their regular medical care. Analyses are limited to the 5,650 applicants receiving fee for service health care. The treatment group had lower Medicare Part A expenditures for the first year of enrollment and averaged over 36 months. Similar results were found combining Medicare Parts A and B expenditures over 36 months. No difference was found in Medicare Part B expenditures. Two of eight demonstration sites showed lower Medicare expenditures for the treatment group. Expenditure reductions did not offset program treatment costs.

Dementia is a highly disabling and destructive condition that has high social and political visibility due to its prevalence (11.3 percent among those 65 and over, 47.6 percent among those 85 or more; Evans, Scheer, Cook, et al., 1990) and its effects on family and community support systems. Much of the analysis of cost for this population has been concerned with imputing the economic value of care provided by family members, documenting acute and long term care costs (such as payments for community-based services and nursing home care), and estimating the indirect costs of caregiving such as from stress and burden of family members and earnings foregone from employment (e.g., Ernst, Hay, 1997; Max, Webber, Fox, 1995; Rice, Fox, Max, et al., 1993; Scharlach & Boyd, 1989; Stommel, Collins, Given, 1994; Weinberger, Gold, Divine, et al, 1993; Wimo, Ljunggren, Winblad, 1997). Some recent work has examined the effects of dementia on annual Medicare expenditures (Gruenberg, Kaganova, Hornbrook, 1996; Pope, Adamache, Khandler, Walsh, 1996; Weiner, Powe, Weller, Shaffer, Anderson, 1998).

The present paper considers whether participation in a case management program by persons with dementia affected their total Medicare expenditures. Involvement in the case management program may have affected the quality of primary care through improved patient advocacy, monitoring of health status among clients and caregivers, and provision of instrumental support to caregivers.

Demonstration Program

The Medicare Alzheimer's Disease Demonstration and Evaluation (MADDE) consisted of two basic components. One was the assignment of demonstration treatment subjects to a case manager (either a social worker or nurse), who worked with family caregivers to plan and coordinate community services, and when needed, helped train caregivers about disease progression and the evolving commensurate functional assistance tasks that caregivers would have to perform. The second component was access to a special Medicare benefit that allowed for the reimbursement of community care services.

Two case management models were implemented that differed by case manager-to-client ratios and per-month service expenditure ceilings for each client. Model A sites operated with a

target case manager-to-client ratio of 1:100 and had a monthly community service reimbursement limit or cap of $290 to $489 per month per client. Model B sites operated with a target case manager-to-client ratio of 1:30 and had a slightly higher reimbursement limit of $430 to $699 per month per client. The per month reimbursement caps in each model varied by site and over time due to regional cost variations and inflation adjustments.

Regular Medicare services--hospital, skilled nursing, home health, durable medical equipment, physician services, and all other services normally reimbursed under Medicare Parts A and B--continued to be available. Services reimbursed under the demonstration's special benefits included: adult day care; home health aide (not otherwise reimbursed under Medicare skilled home health care); homemaker/personal care; housekeeping; general chore (i.e., heavy cleaning); companion (e.g., friendly visiting, caretaking while caregiver attended educational and/or support groups); home delivered meals; non-emergency transportation for client; adaptive and assistive equipment (not otherwise reimbursed as durable medical equipment under Part B); medical supplies used in conjunction with skilled and unskilled home care; consumable goods (such as incontinence supplies); home repairs and safety modifications to the home. [1] Clients and families, other than Medicaid participants, paid a 20 percent co-payment for demonstration services.

Eight sites, four in each model, participated in the demonstration.[2] The sites became operational in December of 1989 and served clients and their families until November 30, 1994. Eligibility for the demonstration required a physician certified diagnosis of an irreversible dementia (e.g., Alzheimer's disease or vascular dementia), client enrollment in (or eligibility for) both Parts A and B of the Medicare program, and residence in a community setting in the demonstration site's catchment area. Nursing home residents at the time of enrollment were ineligible. Although no

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[1] Additional, but seldom used, services included skilled nursing and rehabilitation nursing therapies (i.e., speech, occupational, physical; home health aide), medical supplies in conjunction with skilled and unskilled home care, and home-delivered meals not otherwise reimbursed by Medicare. Case management and caregiver support services were reimbursed separately from the capped demonstration benefit. These services included caregiver education and training, caregiver support groups, and caregiver transportation to education and support groups. The cost for these treatment group services were included in the administrative budgets of the demonstration programs.

[2] Model A (lower reimbursement-higher caseload) sites were located in: Champaign/Urbana, Illinois; Memphis, Tennessee; Portland, Oregon; and Rochester, New York. Model B (higher reimbursement-lower caseload) sites were located in Cincinnati, Ohio; Miami, Florida; Minneapolis, Minnesota; and Parkersburg, West Virginia.

restrictions were placed on a participant's ability to use community services, persons receiving Medicaid case management services at the time of application (for example, through Medicaid Home and Community-Based Care programs) were generally not accepted into the demonstration.[3] Treatment or control group members becoming eligible for such programs after enrollment remained in the demonstration.

Enrollment into MADDE was voluntary. Recruitment included information about the program being a demonstration and the fact that some applicants would be assigned to a control group.[4] Study subjects were recruited using both physician referral and self-referral. Data on applicants obtained from a screening questionnaire and physician referral form were the basis for establishing eligibility for the program. Those found to be eligible were then randomly assigned by the evaluators to either the treatment group (where they were eligible for case management and service coverage), or into a control group (where they continued to receive their usual care). Once enrolled in the demonstration (either as treatment or control), participants were given a semi-annual reassessment throughout their participation (i.e., to death, to 12 months following a permanent nursing home placement, or to the end of study at 36 months). Clients lost their eligibility for community demonstration services and case management once they had been permanently placed into a nursing home. The intake assessments were conducted via in-person interviews and the reassessments were conducted predominantly via telephone. Medicare claims data for each study subject also were obtained for the period starting 12 months prior to enrollment, through the 36 months of participation, death, or health maintenance organization (HMO) enrollment.[5] The

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[3]These individuals were excluded because their case management and benefits were equal to or greater than that available through MADDE. This left the demonstration little opportunity to affect client outcomes. All exclusions occurred prior to randomization.

[4] The demonstration was designed to maximize the project's ability to test the effectiveness of the intervention, not specifically to test its generalizability to the full eligible population. How the requirements of a demonstration may have influenced the decision of the dementia population and their caregivers about whether to apply for the program is unknown. Records were not maintained on individuals who contacted the program, unless they submitted a completed application. Randomized assignment of cases was used to minimize any influence of "choice" among such applicants. This design precluded testing what the treatment effect would have been on a probability sample of the eligible dementia population.

[5]Cases were allowed to continue receiving demonstration services even if they refused continued participation in the evaluation data collection. Participating cases in both the treatment and control groups were tracked for a maximum of 36 months. Once this anniversary date was reached the treatment cases remained in the program (through the program completion date) without further participation in evaluation activities. Similarly, data collection on all control group cases stopped after 36 months. These cases were then eligible for enrollment into the treatment

demonstration enrolled a total of 4,151 participants into the treatment group and 3,944 into the control group.

Hypotheses

The intervention of case management and community service reimbursement had a strong, consistent, and positive impact on the likelihood of using such community-based, long term care services as homemaker/chore, personal care, companion services, and adult day care.[6] Treatment group clients were at least twice as likely as control group members to use one or more of these four services (Newcomer, Yordi, Fox, & Spitalny, 1998).

Increased access to community care and case manager oversight was expected to have a secondary consequence related to health care use and expenditures. Several hypotheses were tested that related to total Medicare health care expenditures for participants, all of whom were in the Medicare fee-for-service system:

- Medicare Part A (largely hospital and skilled nursing home inpatient care) expenditures will be lower in the treatment group compared to controls.
- Medicare Part B expenditures (inclusive of physician and outpatient care, some home health, and durable medical equipment) will be higher in the treatment group compared to controls.
- Total expenditures combining Part A and Part B will be lower in the treatment group compared to controls.
- The treatment effect on Medicare Part A and Parts A+B expenditures will be greater in Model B than in Model A.
- Medicare Part A and Parts A+B expenditures will be lower in the site that used predominantly nurse case managers than in sites with social worker case managers.

Treatment effects were hypothesized to occur in part because of contacts of home care workers with the demented client and their caregivers and regular contacts between case managers

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program, but their care was not monitored by the demonstration evaluation. Control group cases were not informed of this feature until they approached their 36 month anniversary date. This rollover into treatment was done both as a humane gesture for the control group families, and as a convenient means for the programs to maintain their "steady state" caseloads. Applicants during the first 24 months of operation constituted a closed panel of cases for the evaluation. The programs continued to enroll members for two years after that so they could maintain a steady-state client-to-case manager ratio. Evaluation data were not collected on these later enrollee cohorts. Miller, Clay, Fox, & Newcomer (1998) examine attrition from the MADDE project, finding no differences between treatment and control cases in mortality or refusal rates.

[6] Together these services accounted for more than 80 per cent of the services used by demonstration participants (consumable supplies being the other most commonly used benefit).

and caregivers. Such contacts potentially gave case managers on-going information about: (a) the ability of the informal caregiver to provide care and the adequacy of the care they provided; and (b) changes in the health and functional status of the client. Such information, shared with the client's health care providers, may have had a preventive effect in that it could facilitate interventions that reduced avoidable physical deterioration, hospitalization, and emergency room use. Case manager involvement also was assumed to be responsive to the care and support needs of clients and caregivers after critical events such as hospital stays, possibly reducing home health costs and nursing home stays.

The case manager's oversight and patient advocacy were hypothesized to decrease use of hospital-related (mostly Part A) services, and increase use of ambulatory care (mostly Part B) services. Combining Part A and Part B expenditures permits evaluation of whether increased ambulatory care expenditures associated with greater medical management were offset by decreased acute care expenditures for hospital and nursing home care.

Demonstration treatment group participants in the Model B (i.e., higher resource) program sites were hypothesized to have lower health care expenditures than were treatment group participants in Model A (i.e., lower resource) sites, due to the greater availability of care manager resources. The Illinois program, which featured only nurse care managers (and not social workers), was hypothesized to show lower total health care costs than the other sites, due to the greater involvement of demonstration nurses in clinical care. Other sites generally used social workers, although they had access to nurse consultants. (See Chapter 2 of this report for a discussion of operational differences in case management among demonstration sites.)

These hypotheses were tested under varying period and geographic aggregations. Models were estimated for the entire period that participants resided in the community (the "entire exposure period", and for each of up to 3 separate years ("year 1", "year 2" and "year 3", each being a "year period") that they resided in the community. These models were replicated for subjects in all study sites and for each of the eight demonstration sites (communities) considered alone. The focus on study subjects only during their residence in the community (i.e., not in a nursing home)

recognizes that being in the community was a demonstration criteria for receiving case management and home care services. Determining the effect on total expenditures regardless of location (i.e., community vs nursing home) would be confounded by the fact that a case would not be affected by the demonstration's resources after entering a nursing home. The site-specific replications of the analysis recognize that the demonstration's effects may vary due to several factors, including the two different program models, within-model operational differences, and/or practice variations among the communities.

Methodology

The analysis was conducted using data from caregiver assessment interviews linked to Medicare claims records. Claims records were available only for beneficiaries who received their health care through Medicare fee for service reimbursement (n= 5,649), as service encounters within managed care systems (HMOs) are paid on a capitation basis and the Health Care Financing Administration (HCFA) does not require service claims records for those encounters.

The study sample entered the demonstration from December 1989 through November 1991. Assessment data were collected at baseline and semi-annually on each case that continued to reside in the community.[7] The baseline instrument was used for year one analyses. The 12 or 24 month assessments (if the instruments were available or the immediately prior one otherwise) were used for year two and three analyses, respectively. Analyses based on aggregations of cost over more than one year used baseline instruments for client and caregiver covariates.

Although randomization produced highly comparable groups of treatments and controls at baseline, covariates were used in the analysis to increase the precision of the estimates of the effect of the demonstration on Medicare expenditures (by reducing unexplained variance in the outcome variable). Analyses reported elsewhere (Miller, Clay, Fox, Newcomer, 1998) have shown no

[7] Patients enrolling between May and November 1991 constituted a supplemental sample (n=2,310 cases). This sample was selected to assure the evaluation of an adequate sample size for the full 36 months of exposure in the demonstration. For budgetary reasons, assessment data were collected only at baseline, 24, and 36 months for this group. Baseline assessment data were used in all analyses for the first 24 months of exposure for these cases, the 24 month assessment was used in the year 3 analysis.

differences in nursing home placement or sample attrition (due to death or other reasons) between treatment and control groups.

The assessment instruments include data on: client functional status, as measured by a version of the Katz activities of daily living (ADL) scale (Katz, Ford, Moskowitz, Jackson, Jaffee, 1963) and Lawton and Brody's instrumental activities of daily living (IADL) scale (Lawton & Brody, 1969); client cognitive status, as measured by the mini-mental status examination (Folstein, Folstein & McHugh, 1975); client behavioral problems, as measured by an adaptation of the index developed by Zarit, Todd, and Zarit (1986); caregiver ADL and IADL functional status, as measured per above; caregiver burden, as measured by a revised version of Zarit's caregiver burden scale (Zarit, Reever, & Bach Peterson 1980); caregiver depression, as measured by the brief version of the Geriatric Depression Scale (Yesavage, Brink, Rose et al., 1983); and service utilization. The scale ranges are shown in Table 7-1.

Additional client and caregiver data included:

- age
- educational level
- ethnicity
- gender
- income
- insurance
- living arrangement
- marital status
- relationship between client and caregiver

The client measures generally follow the Anderson framework of predisposing, enabling, and need characteristics of clients (Anderson & Newman, 1973). Client measures were expanded to include cognitive impairment (Bass, Looman, & Ehrlich, 1992), behavior problems, and type of housing. Caregiver attributes were added to the model and grouped into parallel predisposing, enabling, and need dimensions. Caregiver attributes were selected from those found in other studies to influence the likelihood of service use.

Insert Table 7-1 about here

Medical diagnoses and Medicare expenditures were obtained from Medicare claims history files.[8] A subset of 16 major diagnostic groups were selected from the 4,000 plus International

[8] For Part A these included hospital inpatient, nursing facility inpatient, hospital outpatient, home health and hospice claims files. For Part B there were physician and home health, and a durable medical equipment (DME) file

Classification of Disease, ninth edition (ICD9-CM) codes used on Medicare claims. These aggregations are shown in Figure 7-1 and follow grouping procedures developed by the Center for Health Economics Research (Pope, et al., 1996). Cases were classified as having the listed chronic condition if there was a qualifying diagnosis on any available record.[9] The period used to identify these diagnoses was inclusive of the 12 months prior to the client's enrollment into the demonstration through their completion of the study or earlier exit due to HMO enrollment (n=129) or death (n=1998). A small group of clients (n=2) also had reduced exposure months because they went into HMOs and subsequently went back to regular Medicare fee-for-service prior to or during their demonstration enrollment.

The operating assumption when using this extended exposure period for diagnostic classification was that any mention of a chronic condition implied that the prevalence of the condition preceded demonstration enrollment.[10] Acute conditions (such as injuries, fractures, or nutritional problems) were not used as control variables as these are associated with incidents or care outcomes. Prevalence rates of chronic conditions treated as risk factors are shown in Table 7-2.

Insert Table 7-2 About Here

Part B files were available for 1991-94, and the DME files were available for 1993 and 1994, because the separate DME file and claim form only began in late 1993. Prior to that these charges were include in the regular Part B claims. Some DME claims continued to appear in the regular Part B file in 1994.

[9]Alternative diagnosis counts were tested to assess prevalence rates. Among these were counts based on a single year and any mention in that year, counts within a single year and at least two mentions in the year; and prevalence rates using claims only from Part A or only from Part B. These comparisons are reported in Appendix 6 of this report. They show that prevalence counts for chronic conditions increased by between 50 and 380 per cent in a given year using both Part A and Part B claims depending on the condition, and by 50 and 280 percent using all periods. The prevalence derived from any one year was at least 50 percent and often 75 percent lower than the prevalence rate obtained using all observed periods. The use of all periods (including one year prior to enrollment) is a conservative attempt to incorporate the identification of comorbid conditions and to minimize underclassification that might occur among cases with truncated exposure. Approximately 30 percent of the cases had only one claims mention of the chronic condition used.

[10] A number of analyses were conducted testing the sensitivity of the prevalence counts to the claim source (i.e., Part A vs. Part B, vs. Part A+B), and the number of months used in classifying a case as having the condition. These are reported in Appendix 6. These analyses, for the study's chronic conditions, show that prevalence rates increased by a multiple of 2 or even 3 comparing all period counts relative to single 6 month or 12 month periods. Similarly, prevalence counts generally doubled when Part A+B counts were compared to Part A only reported diagnoses. Analyses reported by the Medicare Payment Advisory Commission further supports the approach of compiling conditions over multiple years. Their analysis found that 40 percent of cases with a chronic condition in 1994 had no such diagnosis in 1995 (Medicare Payment Advisory Commission, 1998).

In analysis with all sites combined, a set of dummy variables representing the demonstration sites was included, omitting a reference site whose expenditures were closest to the median expenditures among all sites. This facilitates comparison of any one site to the median performance of all sites in the demonstration.[11] Table 7-3 shows the sample size by site.

Insert Table 7-3 About Here

Medicare expenditures, the dependent variable in the analysis, were based on the "allowed amounts" indicated on each claim record. For most claim files this included the amount paid by Medicare, plus deductibles and co-insurance, and any additional amount paid by the recipient. Expenditures were annualized by summing expenditures in the period of interest (i.e., year 1, year 2, year 3, or the entire exposure period (up to 3 years)), dividing the result by the number of exposure days in the period to get a daily rate, and then multiplying by 365 to create an annual rate. In statistical calculations (including group means and regression analyses), cases were weighted by their proportion of exposure days relative to total days in the period in order to ensure that cases with a small number of days and large expenditures did not disproportionately influence results by inflating the mean daily expenditure rate.

Table 7-4 shows the annualized means and standard deviations for each year and entire exposure period in the analysis for Part A, Part B, and the combined Parts A+B expenditures. Annualized expenditures for both yearly periods and the entire exposure period were used in the analysis to assess the sensitivity of the findings to different time intervals. Expenditures during the entire exposure period in the demonstration were specifically used for two reasons: a) whereas single year period expenditures are commonly used as dependent variables in risk adjustment methodologies, the resulting estimates generally have wider variance than those for multiple year

[11] Site visits were conducted at program start-up and close-out as part of the evaluation. One function of these visits was to interview local informants and program staff about service supply and issues relative to changes in supply, competitive advantage of the program to negotiate discounted rates, and problems in access to care for the dementia population. Except for placing Medicaid eligible recipients in nursing homes of their choice, there were no particular service access problems at either baseline or close-out. The programs were not large enough to stimulate new services (e.g., day care) available exclusively to the treatment group members, or to negotiate discounted prices. While these are qualitative impressions, any unmeasured "history" effects that may have influenced the applicant pool or the services they were able to obtain have been controlled for within the study's prospective cohort by the randomization of the applicants. The market area differences in access and use are reflected in the site and site by treatment interaction terms used in the analysis.

period expenditures; and b) in a cohort study (such as this one), there are increasingly fewer cases available in each period after baseline. The combination of more variance and fewer cases results in analyses with lower statistical power than analyses that use data for the full exposure period.[12]

Model development consisted of several steps. The initial step used the client and caregiver attribute interview items shown in Table 7-1. Using total Medicare expenditures as the dependent variable these were reduced to a set of 15 covariates using backward stepwise regression analysis. Interaction effects between treatment and these covariates were tested with none found to be consistently significant. The second step added the 26 chronic condition variables shown in Table 7-2 and used a backward stepwise methodology to adjust for collinearity among chronic conditions that were added at this step. The statistically significant covariates from step 1 and treatment group were forced into this analysis. Both untransformed and log-transformed dependent variables were analysed, and both were found to yield residuals which did not fit a normal distribution. Comparable treatment effects were obtained with both unadjusted and log adjusted expenditures as dependent variables. Only results for the untransformed dependent variable are shown. These are preferred because the parameter estimates can be be interpreted as the effect, in dollar units, of the treatment. To check the robustness of the treatment effect estimates in the presence of the non-normality of the residuals, an analysis was performed in which the most influential cases were removed from the sample. The criterion used for exclusion was a value of Cook's D statistic greater than one. These reestimations did not change the treatment effect findings. [13]

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[12] The observed effect sizes are .06, .03, and .06 respectively comparing Part A, Part B, and Parts A+B treatment and control case expenditures in year 1 for all cases combined; and .08, .05, and .08 respectively comparing Part A, Part B, and Parts A+B treatment and control case expenditures over all periods. An effect size of .06 requires approximately 5300 cases to achieve a statistical power of .75 assuming an alpha of .05 and a one-tailed test. An effect size of .08 has a statistical power of .8 with 3685 cases. An effect size of .02 requires over 34,000 cases to achieve a statistical power of .8. A difference of one-third between the treatment and control group would produce an effect size of .15. With this magnitude of difference, holding the standard deviation constant, as few as 1100 would produce a power level of .8. All but one of the demonstration sites have sample sizes of about 1000 cases. West Virginia with 629 cases requires an effect size of .25 to achieve a power level of .8.

[13] Additionally, a two stage bootstrap regression model was used to identify the likelihood of hospital use and the amount of expenditures among service services (Efron & Tibshirani, 1993). This resampling process consisted of drawing 200 samples, with replacement, for each equation. This approach was used because it makes no distributional assumptions about the residuals. These analyses were initiated starting with the covariates shown in Table 7-1. These results approach the statistical significance of the treatment obtained from the least squares regression.

Because of the presence of statistically significant interaction terms for treatment and site, and regional differences in prevailing service unit prices, separate regression analyses were conducted for each site. This afforded the opportunity to more clearly assess the performance of each program at the level of each community, where randomization produced equivalence between those in treatment and control groups.

Findings

Table 7-5 compares the demonstration's estimated treatment effect using several alternative methods of aggregating the dependent variable data. The first set of rows in Table 7-5 shows estimated treatment effect results from regression models in which all sites are included together. Annualized mean expenditures are shown by year and for the entire exposure period. The other two sets of rows in the table show the treatment effect results based on regression models estimated for each demonstration site (community) considered separately. The site level regression models report only annualized expenditures for the entire exposure period. Three sets of columns are used to show the estimated treatment effect on Medicare annualized expenditures. Separate regression models were estimated for each cell in this table, using the client, caregiver, and health condition covariates shown previously in Tables 7-1 and 7-2. In the interests of presentation parsimony, only parameter estimates for treatment dummy variables are shown.

Several patterns emerge from these results. For all sites combined, there is a statistically significant, negative treatment effect on Medicare Part A and Part A+B expenditures when expenditures are annualized over all periods. For each year considered separately, there is a consistently negative treatment effect on Medicare Part A and Part A+B expenditures, however only the treatment effect for Part A in year 1 is statistically significant at a .05 level. Parameter estimates for the treatment effect on Part A and Part A+B expenditures show a consistent pattern of comparable, if not larger, negative values in year 2 and year 3 models, but these coefficients are not statistically significant.[14]

[14] The failure to achieve statistical significance is partly related to the lower statistical power, discussed in footnote 12, that occurs as sample size diminishes. Another contributing factor is that the standard error increases with fewer cases and within single years, further reducing the treatment effect size.

For all sites combined, the estimates of the treatment effect on Part B expenditures are not statistically significant and show no consistent pattern for direction effect from one year to the next. These findings do not support the hypothesis that the demonstration would lead to higher Part B expenditures for treatments compared to controls, and suggests that the demonstration program did not stimulate or facilitate more access to ambulatory health care than was obtained by those in the control group.

For individual sites, there were few statistically significant differences in expenditure estimates for treatments and controls, regardless of the type of Medicare coverage. However, there was a pattern (albeit nonsignificant) of lowering Part A expenditures among treatment cases in seven of the eight sites. Illinois (a Model A site with nurses as care managers) showed estimates of Part A expenditures that were significantly lower for the treatment compared to the control group. Tennessee (also a Model A site) showed estimates of Medicare Parts A+B expenditures that were significantly lower for treatments compared to controls. No site showed statistically significant differences in Part B expenditures for treatments compared to controls.

The study's fourth hypothesis was that participants in the higher resource demonstration programs (Model B) would have lower Medicare expenditures than participants in the lower resource programs (Model A). This hypothesis was tested initialy using the results of the individual site regression models discussed above. For Model A sites there was a pattern of sizeable and lower Medicare Part A and Medicare Part A+B expenditure estimates for treatments compared to controls, albeit most of these were not statistically significant. For Model B sites, there was no pattern to the results, regardless of type of Medicare coverage. In one Model B site, West Virginia (a predominantly rural site), there was a consistent pattern of sizeable and higher Medicare expenditure estimates for treatments compared to controls, but again, this finding was not statistically significant.

A comparison also was made to determine whether treatment parameter estimates differed between models when the sites within a model were considered as a group. Compared to Model B sites, Model A sites as a group had a significantly greater treatment effect reduction in mean

Medicare Part A expenditures ($p<.018$), and a greater treatment effect reduction in mean Medicare Part A+B expenditures that approached significance ($p<.08$). There was no difference between models in the treatment effect associated with Part B expenditures.

Table 6 shows treatment effects among cases having one of four selected, higher cost chronic conditions (congestive heart failure (CHF), chronic obstructive pulmonary disease (COPD), coronary artery disease, and diabetes). For participants with diabetes, a statistically significant treatment effect was observed for Part A expenditures, which were about $1,200 lower for treatments compared to controls, and similar results approached statistical significance for Parts A+B expenditure estimates. Near significant results were obtained for Part A expenditure estimates for clients with COPD. Otherwise, there were no statistically treatment effects, including for clients with CHF and coronary artery disease.

Conclusions

The Medicare Alzheimer's Disease Demonstration randomly assigned about half of a large group of voluntary applicants into a treatment group that had access to a limited Medicare community care service benefit and routine monitoring and other assistance from a case manager. Those randomly assigned to the control group continued to receive standard care. The demonstration was not expressly designed to affect medical care, but the increased access to community care obtained by those in the treatment group raised the possibility of a secondary effect on health care. Five hypotheses were tested controlling for a variety of attributes of persons with dementia, including functional, cognitive, and physical health conditions, and of caregivers, including relationship to client, and physical and mental health status. These hypotheses were tested for participants that obtained services from the regular Medicare fee-for-service system, and thus for whom there were health care service claim records.

Overall, these findings lend some support to the hypothesis that the demonstration would reduce hospital utilization by treatment (among those using Medicare fee-for-service), compared to control clients. As hypothesized, treatment group members were found to have lower Medicare Part A expenditures than control group members with comparable health status. These annualized

The failure of the treatment program to achieve reduced Medicare expenditures consistently ıong all sites and for all periods suggests the conservative conclusion that the mere presence of a se manager does not assure Medicare expenditure reductions. One reason for a possible absence a consistent effect is suggested by the wide variation in expenditures (especially within single ars). This raises the possibility that case manager involvement may produce at least a short term rease in expenditures for some cases. Further, estimates of the MADDE program effectiveness most favorable when multi-year expenses were averaged together. This suggests that "steady-te" program effects on Medicare expenditures are relatively long term and and require a tained intervention.

Accepting the evidence of lower Medicare expenditures for treatment cases relative to ıtrols in some communities and circumstance, there is still the issue of whether the case nagement and community service intervention, as implemented, was cost effective in lowering se expenditures. In other words, did the cost of the intervention, even in the most favorable s, exceed the cost savings resulting from reductions in Medicare expenditures? The following strates the demonstration performance that would be needed to show cost effectiveness of the nonstration in lowering Medicare expenditures.

A first assumption is that the treatment effect parameter estimates shown in Table 7-5 are ıcators of the true average treatment effects among a cohort of clients over time. A second ımption concerns the average cost of the case management intervention itself. For the sake of plicity, the average annual salary for a full time equivalent case manager is set at $30,000 and administrative overhead, home visit and other operating expenses are equal to the annual salary. a Model A site, with a ratio of 1 case manager per 100 clients, this produces an annual cost per nt of $600 or $50 per month. For the Model B sites with a 1:30 case manager to client ratio the ual cost per client is $2,000 or $167 per month. For the Illinois site, which in actuality had a manager to client ratio closer to 1:50, the annual costs per client would be $1,200 or $100 per ıth.

Based on these rates, Model A sites, with a combination of lower staffing costs and somewhat larger treatment effects would generally show a net savings relative to additional case-management costs. None of the Model B sites reduced average Medicare expenditures enough to offset these estimated staff and operational costs. This is true using both the actual treatment parameter estimates for each site, and the average treatment parameter estimates among all Model B sites combined. Even if the Model B per client cost were set at the Model A rate, only one site would show net savings.

The preceding comparisons do not include the cost of the additional Medicare benefits obtained by treatment group participants under the demonstration waiver for community care services. These averaged more than $200 a month in Model A and $300 per month in Model B. When these costs are added to those of the case manager and other operational costs, none of the sites produce a net average Medicare savings, as calculated given the assumptions outlined above. Moreover, there were no offsetting demonstration savings from any reductions in nursing home care (Miller, et al., 1998).

A substantial change in performance would be needed among all sites to achieve budget neutrality. Assuming that community services remain at an average of $200 per month and that effective case management can be delivered for an average monthly cost per client of $25 (half the estimated rate under the existing Model A operation) an average of $2,700 in annual Medicare expenditure savings would be necessary just to reach budget neutrality. This rate means that Medicare expenditure reductions due to a MADDE-type project would be $2,000 or more short of this target figure in seven of the eight sites, and $1,000 short in the other.

As with many other national demonstrations a number of questions are raised that highlight either: a) limitations of the design of the particular project intervention; or b) methodological issues that might inform further work in this area. One limitation of this study is that results pertain only to beneficiaries that use the regular Medicare fee-for-service system. In that system, it may be difficult or impossible to create appropriate financial incentives to reduce overall costs, unlike the Medicare HMO sector, where there is an incentive to reduce costs.

A second limitation is that the program was not expressly designed for case managers to work with health care providers in the identification and management of high risk cases. Although this occurred to varying degrees within each site, including in response to the request of family members and providers, it was most explicit and common only in the Illinois nurse case manager program. Although case attrition in MADDE over three years due to death and nursing home placement suggests that the demonstration was successful in identifying a higher-cost population, there were only marginal gains for those in the treatment group over those in the control group. This suggests that further refinement in case targeting may be an important continuing step to reducing per client cost, and an essential step in beginning to provide a cost effective program. Examining caregiver attributes and their relationship to preventable health care episodes (such as injuries, medication mismanagement, inadequate nutrition or skin care), issues not examined in these analyses, may be a productive area for further research into case targeting risk factors.

Another needed refinement is in the clinical efficacy of treatment for high risk cases, whether these result from chronic conditions or other factors. Finding a high risk case does not by itself assure that an effective care plan can be designed or implemented (although the statistically significant treatment effect for patients with diabetes suggests that successful interventions can occur). Exploration of possible modes of communication and collaboration between caregivers (whether family members or paid providers) and care managers, and between care managers and health care providers was not a subject tested in depth in MADDE. Further work in this area may be productive. Also important is gaining a better understanding of the health care use of those with dementia and other chronic conditions. What portion of the expenses incurred by this population are resultant from poorly managed chronic conditions? What practice interventions may be helpful in improving this care?

Finally, relative to the question of quantitative evaluation of the cost effectiveness of programs such as MADDE, there is a need to be cognizant of the differential findings that arise among individual sites, and over single versus multiple years. Sampling theory speaks to concerns like homogeneity bias in cluster samples and the issue of within-group versus between-group

variation. Sites and time periods are clusters, and expenditures by an individual within the same period often are not independent events and they may be affected by community-specific practice patterns. While this demonstration had sufficient power to detect an effect size of .15 in seven of the eight sites, the total number of sites (four in each model) was insufficient to address the within-and-between group problem. More fixable, from a research cost standpoint, are the time aggregations that are used. The findings from this paper suggest that treatment effects may be more discernable when expenditures are averaged over multiple years rather than using only the events of a single year. Average expenditures over time also are likely to be a better reflection of the performance of a steady-state program. Such a finding may have implications for risk adjustment methods based on a single year of expenditure data, as well as for the future evaluation of interventions.

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Table 7-1: Characteristics of the Analysis Sample

Characteristic	Treatment Group Count	Treatment Group %	Control Group Count	Control Group %
Client Age				
• 20-64	45	1.6	48	1.7
• 65-69	280	9.7	253	9.1
• 70-79	1219	42.4	1160	41.8
• 80-84	693	24.1	700	25.2
• 85-90	452	15.7	451	16.3
• 90+	186	6.5	163	5.9
Client Gender (female)	1770	61.6	1650	59.5
Client Race				
• White	2471	85.9	2379	85.7
• Black	297	10.3	288	10.4
• Hispanic	92	3.2	95	3.4
• Other	15	0.5	13	0.5
Client Lives with relatives	1024	35.6	1007	36.3
Client Lives in own home	1851	64.4	1768	63.7
Client Income				
• Less than $5,000	242	8.4	212	7.6
• $5,000 - 9,999	743	25.8	780	28.1
• $10,000-19,999	973	33.8	949	34.2
• $20,000-30,000	425	14.8	379	13.7
• $30,000+	354	12.3	328	11.8
• Unknown	138	4.8	127	4.6
Medicaid recipient in any period	216	7.5	213	7.7
Medicare Supplemental Insurance	1333	46.4	1250	45.0
Entered HMO (after baseline)	65	2.3	64	2.3
Client Activities of Daily Living (ADL) Limitations[a]				
• 0-1	543	18.9	554	20.0
• 1.5-2	459	16.0	450	16.2
• 2.5-3	390	13.6	362	13.0
• 3.5-5	647	22.5	595	21.4
• 5.5-8	486	16.9	476	17.2
• 8.5-10	350	12.2	337	12.1
Client Instrumental Activities of Daily Living (IADL) Limitations[b]				
• 0-3	171	5.9	177	6.4
• 3.5-5.5	515	17.9	534	19.2
• 6-6.5	456	15.9	412	14.8
• 7-7.5	787	27.4	766	27.6
• 8	946	32.9	885	31.9
Client Mini Mental Status Examination (MMSE) Score[c]				
• 0	306	10.6	278	10.0
• 1-5	244	8.5	226	8.1
• 6-10	292	10.2	292	10.5
• 11-15	448	15.6	469	16.9
• 16-20	617	21.5	573	20.6
• 21-25	543	18.9	500	18.0
• 25-30	256	8.9	261	9.4
• Missing	169	5.9	176	6.3
Client Behavior Problems[d]				
• 0-4	439	15.3	385	13.9
• 5-7	625	21.7	577	20.8
• 8-10	717	24.9	723	26.1
• 11-13	649	22.6	609	21.9
• 14-19	430	15.0	471	17.0
• Missing	15	0.5	10	0.4

[a] ADL score is based on needing none, some or maximum assistance. Scores range from 0 (low) to 10 (high) impairment.

[b] IADL score is based on needing none, some or maximum assistance. Scores range from 0 (low) to 16 (high) impairment.

[c] Mini Mental Status Examination values can range from 1 to 30. Lower scores are indicative of greater impairment.

[d] The Behavioral Problems Index ranges from 0 to 19. The higher the score, the greater the number of behavior problems.

Table 7-1. Characteristics of the Study Sample (continued)

Characteristic	Treatment Group Count	%	Control Group Count	%
Caregiver Relationship to Client and Gender				
• Husband	465	16.2	410	14.8
• Wife	839	29.2	827	29.8
• Daughter	855	29.7	787	28.4
• Son	237	8.2	242	8.7
• Daughter in law	105	3.7	119	4.3
• Female relative	179	6.2	198	7.1
• Other	185	6.4	168	6.1
• Missing	10	0.3	24	0.9
Caregiver Age				
• Under 70	1707	59.4	1673	60.3
• 70-74	350	12.2	335	12.1
• 75-79	336	11.7	329	11.9
• 80-84	236	8.2	223	8.0
• 85+	111	3.9	103	3.7
• Missing	135	4.7	112	4.0
Caregiver Income				
• Less than $10,000	228	7.9	250	9.0
• $10,000- $40,000	721	25.1	667	24.0
• $40,000+	407	14.2	412	14.8
• Income joint with that of client	1304	45.4	1237	44.6
• Missing	215	7.4	209	7.6
Caregiver Educational Attainment				
• Less than High School	603	21.0	572	20.6
• High School Graduate	844	29.4	820	29.5
• Some College	659	22.9	669	24.1
• College Graduate	681	23.7	648	23.4
• Missing	88	3.1	66	2.4
Caregiver Health status (fair/poor)	660	23.0	641	23.1
Caregiver ADL limitations[a]				
• 0	2376	82.6	2288	82.5
• 1 or more	413	14.4	422	15.2
• Missing	86	3.0	65	2.3
Caregiver IADL limitations[b]				
• 0	1932	67.2	1898	68.4
• 1	269	9.4	246	8.9
• 1+	586	20.4	562	20.3
• Missing	88	3.1	69	2.5
Caregiver Stress and Burden Scale[e]				
• 0-6	559	19.4	589	21.2
• 7-10	544	18.9	487	17.5
• 11-14	602	20.9	603	21.7
• 15-18	558	19.4	524	18.9
• 19-28	529	18.4	506	18.2
• Missing	83	2.9	66	2.4
Caregiver Depression Scale[f]				
• 0	228	7.9	238	8.6
• 1-2	766	26.6	747	26.9
• 3-4	648	22.5	632	22.8
• 5-6	456	15.9	448	16.1
• 7-8	302	10.5	305	11.0
• 9-15	383	13.3	329	11.9
• Missing	92	3.2	76	2.7

Note: Chi-square analyses were used to test significant differences between groups. No such differences were found.

[e] Scores range from 0 - 36. Lower scores equal lower stress and burden

[f] Scores range from 0 - 15. Lower scores reflect a greater likelihood of depression.

Table 7-2: Prevalence of Selected Chronic Health Conditions Found on Any Medicare Claims Record

Conditions	Treatment Group # w/condition	Treatment Group %	Control Group # w/condition	Control Group %
Cancer (except minor skin cancer)	546	19.0	542	19.5
Diabetes (w/ and w/out complications)	614	21.4	621	22.4
Eyes/Ears				
• Blindness or substantial vision defect	52	1.8	44	1.6
• Hearing loss	132	4.6	122	4.4
• Vertigo/dizziness	263	9.1	282	10.2
Heart and Vascular Systems				
• Aneurysms (other than CVA)	45	1.6	45	1.6
• Cerebrovascular aneurysm	693	24.1	647	23.3
• Cerebrovascular (other) disease events	1159	40.3	1096	39.5
• Congestive heart failure	811	28.2	760	27.4
• Coronary artery disease	923	32.1	919	33.1
• Hypertension (any)	1335	46.4	1211	43.6*
• Myocardial infarction	257	8.9	272	9.8
• Peripheral vascular disease	745	25.9	708	25.5
Liver/gall bladder/pancreas diseases	256	8.9	261	9.4
Musculo-skeletal system				
• Intervertebral disorders	282	9.8	259	9.3
• Osteoarthritis related disorders	700	24.3	735	26.5
• Other arthropathies (including rheumatoid arthritis)	889	30.9	908	32.7
• Other connective tissue disorders	85	3.0	89	3.2
Nervous System				
• Degenerative nervous system conditions	484	16.8	464	16.7
• Paralysis (excludes coma or head injuries)	208	7.2	221	8.0
• Peripheral nerve problems	135	4.7	146	5.3
Pulmonary System				
• COPD/asthma/emphysema	769	26.7	726	26.2
• Tuberculosis (pulmonary only)	57	2.0	51	1.8
Renal system diseases	439	15.3	409	14.7

*$p<.05$ using Fisher's statistical test, 2-tailed.

COPD refers to chronic obstructive pulmonary disease. The diagnostic categories included in each of the listed conditions are shown in Figure 1.

Table 7-3: Number in Analysis Sample by Site and Available Claims Data

Sites	Total Enrolled[a]	Part A Eligible[b]	Parts A+B Eligible
Model A Total	**3965**	**2995**	**2883**
• Treatment	2029	1520	1467
• Control	1936	1475	1416
Illinois	**999**	**920**	**881**
• Treatment	515	475	454
• Control	484	445	427
New York	**1048**	**761**	**732**
• Treatment	530	383	374
• Control	518	378	358
Portland	**932**	**430**	**414**
• Treatment	485	212	207
• Control	447	218	207
Tennessee	**986**	**884**	**856**
• Treatment	499	450	432
• Control	487	434	424
Model B Total	**4130**	**2655**	**2518**
• Treatment	2122	1355	1288
• Control	2008	1300	1230
Florida	**1157**	**726**	**675**
• Treatment	593	371	346
• Control	564	355	329
Minnesota	**1417**	**604**	**585**
• Treatment	738	314	305
• Control	679	290	280
Ohio	**927**	**825**	**779**
• Treatment	481	423	401
• Control	446	402	378
West Virgina	**629**	**500**	**479**
• Treatment	310	247	236
• Control	319	253	243
Total All Sites	**8095**	**5650**	**5401**
• Treatment	4151	2875	2755
• Control	3944	2775	2646

[a]The total sample excludes persons enrolled into the demonstration who died or entered a nursing home within the first 30 days after enrollment, and persons who were living in nursing homes at the time of enrollment and who failed to return to the community. It includes persons who were enrolled in an HMO.

[b]The difference in cases between the total sample and those eligible for Part A reflects the number of enrollees who were members of an HMO at baseline. The difference between the Part A sample size and the Parts A+B sample size occurs because Part B claims were unavailable until January 1, 1991. Any demonstration plan member dying or joining an HMO prior to that date did not have Part B claims records available, consequently Parts A+ B expenditures could not be calculated prior to that date.

Table 7-4: Annualized Mean Medicare Expenditures by Period

Period	Part A Total	Part A Treatment	Part A Control	Part B Total	Part B Treatment	Part B Control	Parts A+B Total	Parts A+B Treatment	Parts A+B Control
Year 1									
Total Cases	5648	2874	2774	5151	2641	2510	5151	2641	2510
Mean Expenditures	5284	4983	5596	1791	1759	1825	7526	7169	7898
Standard deviation	9695	9626	9760	2484	2572	2387	11544	11751	11316
Year 2									
Total Cases	3665	1870	1795	3665	1870	1795	3665	1870	1795
Mean Expenditures	6023	5743	6317	1673	1634	1714	7697	7378	8032
Standard deviation	10497	9948	11036	2687	2638	2739	12463	11812	13105
Year 3									
Total Cases	2255	1184	1071	2255	1184	1071	2255	1184	1071
Mean Expenditures	7067	6791	7367	1833	1736	1939	8901	8526	9305
Standard deviation	12364	12218	12524	3006	2931	3084	14458	14127	14813
All Periods									
Total Cases	5649	2875	2774	5170	2652	2518	5170	2652	2518
Mean Expenditures	5862	5578	6161	1758	1709	1810	7898	7555	8260
Standard deviation	6922	6822	7020	1911	1930	1890	8533	8486	8576

Means are based on an annualization of expenditures for each case alive and living in the community at the start of the period shown. Counts differ in year 1 between Part A and Part B due to unavailable physician payment records prior to 1991. Partial use in a period was annualized by dividing total expenditures in the period by the number of exposure days and multiplying by 365. Statistical calculations further weighted each case by the proportion of days in the exposure period.

Table 7-5: Demonstration Treatment Effects on Medicare Expenditures By sample, data period, and type of Medicare Coverage

Sample	Medicare Part A N	Medicare Part A Treatment Effect	Medicare Part A 95% Confidence Interval	Medicare Part B N	Medicare Part B Treatment Effect	Medicare Part B 95% Confidence Interval	Medicare Part A and B N	Medicare Part A+B Treatment Effect	Medicare Part A and B 95% Confidence Interval
All Sites									
All Periods	5,649	-493*	-923 to -63	5,170	-61	-1,823 to 61	5,170	-570*	-1,133 to -8
Year 1	5,648	-535*	-1,058 to -11	5,151	-20	-172 to 131	5,151	-572	-1,300 to 156
Year 2	3,665	-345	-1,048 to 358	3,665	14	-159 to 188	3,665	-329	-1,154 to 496
Year 3	2,255	-624	-1,665 to 417	2,255	-225	-467 to 17	2,254	-848	-2,047 to 350
Model A Sites									
Illinois, All Periods	920	-819*	-1,630 to -7	825	-17	-253 to 218	825	-852	-1,956 to 251
New York, All Periods	761	-632	-1,706 to 443	707	-38	-277 to 202	707	-768	-2,216 to 681
Oregon, All Periods	430	-1,156	-2,769 to 457	403	114	-205 to 433	403	-670	-2,718 to 1318
Tennessee, All Periods	884	-1,233	-2,568 to 102	826	-333*	-640 to -26	826	-1,641*	-3,262 to -20
Model B Sites									
Florida, All Periods	725	-390	-1,902 to 1122	657	220	-393 to 833	657	39	-2,106 to 2184
Minnesota, All Periods	604	-279	-1,600 to 1,047	554	-269	-602 to 64	554	-797	-2,513 to 920
Ohio, All Periods	825	-245	-1,405 to 915	734	-24	-360 to 313	734	-284	-1,926 to 1357
West Virgina, All Periods	500	521	-1,419 to 2,450	464	130	-292 to 551	464	1,026	-1,379 to 3431

*probability value <.05

Sample size for Medicare Part A only analyses is larger than for analyses combining Medicare Parts A and B-because Part B records were unavailable before 1991. All expenditure estimates are on an annual basis. Annualization of the 3 dependent variables was calculated using total expenditures divided by total exposure days, and multiplied by 365. Regression analyses used cases weighted by the ratio of exposure days in the period to total possible days in the period. All dollar estimates are rounded to whole numbers.

Table 7-6: Demonstration Treatment and Medicare Expenditures for Selected Chronic Conditions, All Sites Combined and Period in the Community Only

Conditions	n	Medicare Part A	95% Confidence Interval	n	Medicare Part A+B	95% Confidence Interval
Congestive Heart Failure	1,570	-424.4	-1468.3 to 619.6	1,475	-407.2	-1778.1 to 963.7
COPD	1,494	-950.4	-1976.8 to 76.1	1,424	-1034.6	-2404.5 to 335.3
Coronary Artery Disease	1,841	-77.0	-922.0 to 768.0	1,738	19.6	-1070.5 to 1109.8
Diabetes	1,234	-1241.6*	-2341.7 to -141.8	1,145	-1378.3	-2797.4 to 40.7

*p<.05

Expenditures are derived combining both Medicare Parts A and B claims. Expenditures are using total expenditures divided by total exposure days, and multiplying this result by 365. Regression analyses further weighted cases by their proportion of days in the period.

Figure 7-1: Listing of Chronic Conditions and their Defining Diagnostic Codes

Cancer (exc minor skin cancer)
Any diagnosis: 14 15 16 170-1729 174-179 18 1800 1801 1808 1809 181 1820 1821-1849 185 19 190 1940-1991 2 20 23 230 239 7950 7951

Cerebrovascular aneurysm (CVA)
Any diagnosis: 436 4373

Cerebrovascular Disease Events, Other
Any diagnosis: 438 439

Congestive Heart Failure (CHF)
Any diagnosis: 39891 40403 40411 40491 40493 428 4280 4281 4289

Coronary Artery Disease
Any diagnosis: 4110 4111 4118 41181 41189 412 4130 4131 4139 4140 41400 41401 4148 4149 4297

Diabetes (with and without complications)
Any diagnosis: 25 250 25000 25001-3 25010-13 25020-2323 25030-33 25040-43 25050-53 25060-63 25070-73 25080-83 25090-93 2510-13 3620 36641 7902 7915 7916

Liver/Gall Bladder/Pancreas Disease
Any diagnosis: 070 1514 251. 2518 570 571 5710-19 572 5720-28 573 5730 5734 5738 5739 574 57400 57401 57410 57411 57420 57421 57430 57431 57440 57441 57450 57451 575 5750 5751-59 576 5760-69 577 7824 7891 7895 7904 7905 7933 7948

Myocardial Infarction (AMI)
Any diagnosis: 41 410 4100 41000 41001-2 4101 41010-12 4102 41020-22 4103 41030-32 4104 41040-42 4105 41050-52 4106 41060-62 4107 41070-72 4108 41080-82 4109 41090-92 412

Nerve problems, Paralysis (excludes coma or injuries)
Any diagnosis: 342 3430-34 3438 3439 344 3440 3441 3443 3444 3446 34460 3448 3449 7814??

Nerve problems, Peripheral (excludes paralysis)
Any diagnosis: 350-7 7307 9529 953-56

Nerve problems, Other Degenerative nervous system conditions
Any diagnosis: 013 014 015 332 3320 335 336 337 340 341 342 343 344??

Other Arthropathies including rheumatoid arthritis
Any diagnosis: 7110-16 7193-99 720-21

Pulmonary disease, COPD/Asthma/Emphysema
Any diagnosis: 01140 1370 491 4910-12 49120 49121 4918 4919 492 4920 4928 493 49300 49301 49310 49311 49320 49321 49390 49391 494 496 5081 5100 5109 515 5183

Renal disease
Any diagnosis: 0160 27410 27411 403 404 58 590 591 592 593 7880 7885 7944 866

Substance Abuse/Alcoholism
Any diagnosis: 291 292 303-5 3050 3052-59 4255 571 5710 5711-13 5715 5353 7903

Vascular disease, Peripheral
Any diagnosis: 440 4400 4401 4402 44020 44021 44022 44023 44029 4408 4409 443 4430 4431 44381 44389 4439 4460-62 44620-21 44629 4463 4464-67 4470-81 4489 5570 5571 5579 7854

APPENDIX ONE

ALZHEIMER'S DISEASE AND RELATED DISORDERS AS A PUBLIC POLICY ISSUE

BACKGROUND

Alzheimer's disease is a progressive dementia primarily occurring in the later years of the life span, but it may appear as early as age 40. Persons with the disease are characterized by disorientation as to time, place, and person; deterioration of personality; and physical incapacitation. The prevalence of Alzheimer's disease is increasing because life expectancy is increasing. Over 10 percent of the total U.S. population age sixty-five or older had Alzheimer's disease in 1990 (3.75 million cases); nine million Alzheimer's disease cases are projected by the year 2040 (Evans, 1990). The estimated prevelance of severe dementia, including Alzheimer's disease, for persons age eighty-five or older (the oldest old) is much higher, ranging from 25 to 45 percent (U.S. Congress Office of Technology Assessment, 1987). Almost half of all skilled nursing facility patients have severe dementia (Rovner, 1986; National Center for Health Statistics, 1991). While Alzheimer's disease is the leading cause of dementia in adults, stroke and traumatic brain injury are also frequent causes of dementia. The U.S. prevalence of stroke is estimated at 2.9 million cases and the U.S. prevalence of traumatic brain injury is estimated to range from 1 million to 1.8 million cases (Alzheimer's Association, 1993; National Institute for Neurological Discorders and Stroke, 1990).

Alzheimer's disease places substantial financial burdens on the afflicted patient, his/her family, and the community. The onset of the disease is usually slow and gradual. Over time, the disease follows a deteriorating course. Persons who originally managed routine household chores generally have problems with cognitive and functional activities as the disease progresses, and may rely on others for assistance in carrying on many activities of daily living. This cognitive, functional, and behavioral deterioration usually culminates in the need for institutionalization, often for a period of several years. Persons with Alzheimer's disease and related disorders routinely have cognitive (Reisberg, 1983) and self-care deficits (Skurla, Rogers and Sunderland, 1988; Teri, Larson and Reifler, 1988). They may also have psychiatric and behavioral problems such as depression (Reding, Haycox and Blass, 1985; Reifler, Larson and Teri, 1986), wandering, and disruptiveness (Haley, Brown and Levine, 1987; Rabins, Mace and Lucas, 1982). Age related chronic comorbid conditions, most prevalent among the very old (Rice & Feldman, 1983; Hoffman & Rice, 1997), are likely to exacerbate these problems. In addition to the substantial cognitive, affective, and behavioral deficits affecting people with Alzheimer's disease, they are also at risk for problems associated with living alone in later life (Arnsberger Webber, Fox, Burnette, 1994). Such problems include economic insecurity (Kasper, 1988), loneliness and depression (Kovar, 1986; Reding et al., 1985), and an increased need for community based or institutional long term care services (Branch & Jette, 1982; Blake et al., 1980; Coe et al., 1985; Greene & Ondrich, 1990; Wan, 1987). State and federal governments shoulder some of the costs of caring for persons with Alzheimer's disease, largely through Medicare and Medicaid (Helbring, 1985). However, a large proportion of costs are borne by families who provide unpaid informal care (Brody, 1989; Hu et al., 1986; Rice et al., 1993). Family members are generally the primary providers of informal care to the frail aged (Shanas,1979) and spouses and adult children are the usual caregivers (Cantor, 1983; Johnson & Catalano, 1983).

Hu, Huang, and Cartwright (1984) concluded that the total cost of illness in the United States of this population was $102.2 billion in 1983 and the marginal cost (additional cost due to dementia only) was $77.6 billion. This study suggests that on a per capita basis, the costs of dementia are $22,458 per year for a nursing home resident, $14,815 for a severely demented person at home, and $6,515 for a mild to moderately demented person at home (Hu, et al., 1986). This study did not consider non-elderly dementia patients nor did it include the cost of health care services such as hospitals, physicians, and drugs (Cartwright, et al., 1984). Hay and Ernst (1987) have estimated that the overall cost of Alzheimer's disease for all patients diagnosed in 1983 was between $27.9 billion and $31.2 billion. Their one-year per person formal cost estimate was $8,196. Inflated to

1990 dollars, this equals $16,264. They also estimated the annual U. S. 1991 prevelance costs of Alzheimer's disease to be $67.3 billion (Hay and Ernst, 1994).

Rice et al. (1993), estimated that the annual formal and informal costs of caring for a person with Alzheimer's disease in community and institutional settings were not significantly different ($47,083 versus $47,591). However, the distribution of costs was quite different. For institutionalized patients, informal services comprise 12 percent of the total costs of care while 88 percent is attributable to formal services. Conversely, for patients residing in the community, 73 percent of the total cost of care is for informal assistance while 27 percent is for formal services. On average, Medicare covered 12 percent of the total cost of formal care (including hospital, nursing home, physician visits, medications, medical supplies, and social services) provided to community resident persons as a result of Alzheimer's disease while Medicaid covered less than one percent of the costs. Private payments for formal care are considerably higher than public payments -- 65 percent (mainly self-pay) compared with 35 percent (mainly sources other than Medicare and Medicaid such as VA and state, county, and city-funded services).

Utilization of Health and Social Services by Persons with Alzheimer's Disease and Related Dementias and Their Caregivers

Since the early 1960s many formal, non-institutional medical, social, and health related services for the elderly have been provided under the rubric of "community-based long term care." With the implementation of the Medicaid, Supplemental Security Income and Medicare programs, coupled with the growing number of elderly persons, service demand has increased and has resulted in rising public and private costs for community-based long-term care. The formal (piad) costs of caring for people with Alzheimer's disease and related disorders are expected to continue to increase, peaking in the first quarter of the next century due to: 1) general economic inflation; 2) annual increases in U. S. health costs exceeding the inflation rate; 3) increasing numbers of people in the 85 years and over age group; 4) increases in the expected life span; and 5) increasing numbers of people in the non-elderly disabled population receiving Medicare benefits (Arnett et al., 1986; Manton and Liu, 1984). These social forces are also expected to contribute substantially to increases in long-term care costs as larger proportions of the population live with the effects of chronic conditions such as Alzheimer's disease for longer periods of time (Hoffman et al., 1996)..

The impact on the formal long-term care service system of assisting persons with dementing disorders is potentially great. By the year 2000, 1.3 million cases of severe dementia are projected in the oldest-old age group alone, and a total of 2.4 million cases among persons aged 65 or older, (U.S. Congress, 1987). Prevalence rate estimates for Alzheimer's disease are as high as 47 percent of those 85 and older living in the community (Evans, et al., 1989). It has been estimated that for every person in a nursing home, there are two comparably disabled elderly persons living in the community who utilize informal family supports (Kane & Kane, 1987). Research has shown that for community dwelling elderly with substantial disability, three-fourths are cared for informally in the community and that 85 percent of needed financial or other help is provided by the family (Malone Beach & Zarit, 1991; Brody, Dempsey, & Pruchno, 1990; Callahan et al., 1980; the LTC Campaign, 1993). Furthermore, lack of familial and other informal supports has been found to be a major predisposing factor in the institutionalization of older persons with health or functional problems (Colerick & George, 1986; Deimling, 1994; Morycz, 1985; Pruchno, Kleban, Michaels, & Dempsey, 1990; Brody, 1985).

Informal support, or caregiving, refers to the activities and experiences involved in attending to and/or providing help and assistance to relatives or friends who are unable to provide for themselves (Pearlin et al., 1990; Eisdorfer, 1991). The primary caregiver is usually a spouse or, if the spouse is not available, an adult daughter. In the absence of both, another relative assumes the major caregiver responsibility and, where no family members are available, frail elderly people turn to neighbors or friends for assistance (Stone, Cafferata, & Sangl, 1987). About one-half of

primary informal caregivers provide this care with no outside assistance while only an estimated 10 to 20 percent of family caregivers use formal services through public or private agencies (American Association of Retired Persons, 1988; Brody, 1990; Gwyther, 1990). These estimates are of special concern because of the rapid increase in the older population in general (Cantor & Liu, 1984).

While both the role of informal care in assisting demented elderly people and the effect of such care on caregivers has been documented, the role of the formal system has received less attention. Research has focused on the elderly's utilization of health care and social services (Coulton & Frost , 1982; Branch et al., 1981; Shapiro & Roos, 1982; Krout, 1983; Soldo, 1985; Harel, 1985), but few studies have been conducted specifically on the service utilization patterns of persons with dementia. Much of the research in this area is characterized by non-probability samples. Generally, caregivers have been identified through their membership in support groups or through a clinic that treats dementia patients (Chenowith and Spencer, 1986; Filinson, 1985; Barnes at al., 1981; Fox & Webber, 1993; Ginther, Webber, Fox, & Miller, 1993a; 1993b; Ginther, Humphers, Fox & Miller, 1993; Arnsberger Webber, Fox & Burnette, 1994; Ginther, Webber, Fox and Miller, 1994). The use of formal services is often included in definitions of social support and is thought to aid in reducing caregiver stress and burden by providing, at a minimum, respite from the duties of caregiving. However, based on prior research, caregivers consistently underutilize the formal services available to them, even when they are provided at low cost (cf., Biegel, Bass, Schulz, & Morycz, 1993; Caserta, Lund, Wright & Redburn, 1987; Bass & Noelker, 1987; George, 1987; U. S. Congress Office of Technology Assessment, 1990; Swan & Estes, 1990; Parris-Stephens, 1993). Despite the generally high levels of distress among caregivers to Alzheimer's patients, their rate of formal service use is lower than that for caregivers to older adults with other illnesses (U. S. Congress Office of Technology Assessment, 1990).

While need for a service appears to be the major predisposing factor in service utilization, a number of reasons for nonuse have been identified, including inappropriateness of the service provided; stress related to coping with any additional factors, including the presence of an in-home worker, in an already stressful situation; lack of knowledge of service availability; lack of knowledge about how to arrange for services; the cost of services; the fear of future illness-related costs that made caregivers reluctant to spend money in the present; concern that others would view the caregiver negatively if they obtained caregiving help; embarrassment at the care recipient's behavior; or the fear of upsetting the care recipient (Arnsberger Webber et al., 1994; Logan and Spitze, 1994; Enright, 1991; Scharlach, 1989; Starett et al., 1989; Krause, 1988; McCaslin, 1988; Bass and Noelker, 1987; Caserta et al., 1987; Stone and Cafferata, 1986; Hooyman et al., 1985; Soldo, 1985; Evashwick, et al., 1984; McCauley and Arling, 1984; Krout, 1983; Daatland, 1983; Snider, 1980). In addition, some caregivers indicate that they don't need services, either because they do not feel burdened or because they do not regard their relative with dementia as having a disease (Parris-Stephens, 1993).

Caserta et al. (1987) notes that little is known about the utilization patterns of caregivers of dementia patients when services are available. From anecdotal reports by caregivers and the few available research studies, several general impressions can be garnered. The degree of involvement of the caregiver both with the patient and available resources (e.g., income, information, informal support) must be examined in relation to service utilization, and evidence suggests that caregivers may have difficulty determining what their needs actually are (Caserta et al., 1987; Zarit, Todd and Zarit, 1986). Perhaps more for caregivers of persons with Alzheimer's disease than for other caregivers of the frail elderly, the decision to utilize or not utilize formal services (especially respite care) may be related to the presence or absence of a variety of factors related to the caregiving experience. Researchers have also examined the degree to which institutional care is used by demented persons. Data suggest that persons with dementia use a disproportionate amount of medically oriented skilled nursing care. It is estimated that over 50 percent of nursing home residents have some form of dementia (Arie, 1975).

There are special issues for people with Alzheimer's disease that will certainly have an effect on their non-institutional service utilization patterns. First is the problem of the mental status of patients. As the judgement of the person with Alzheimer's disease deteriorates, an increasing amount of decision-making must be undertaken by the patient's caregivers, often family members who may or may not exhibit the same service utilization patterns as the older individual him/herself (Stone and Cafferata, 1986). A second problem complicating research efforts is the lack of available services for people with Alzheimer's disease. While many community based long term care services are being developed throughout the country, often these are not appropriate for, or do not accept, persons with Alzheimer's disease and related disorders. Standard public assistance programs such as homemaker/chore programs are so limited in both quality and quantity of available service then some caregivers report it does not help to use them (Hooyman, Gonyea and Montgomery, 1985; Kaye, 1984). A third problem is the lack of reimbursement for health care services for people with Alzheimer's disease. A national survey whose respondents were caregivers of the elderly found that the majority (57.1%) reported adjusted family incomes in the low to middle range (Stone and Cafferata, 1986). Nonetheless, surveys indicate that most services used by these people have to be privately purchased (U. S. General Accounting Office, 1977; Doty, 1985).

Even for Medicaid eligible households coverage for care is available only when a family has decided to institutionalize the patient. Except for limited waiver programs, Medicaid dollars cannot be used to purchase community services (Estes and Benjamin, 1985). Because of these factors, service utilization patterns may be affected to an unusual degree in this population by issues of cost. One study on support groups concluded "it was often apparent during group sessions that caregivers needed (but did not use) concrete assistance such as in-home chore services, sitters and home health care which they could not afford and were not eligible for on any reduced charge or fee basis" (Haley, Brown and Levine, 1987:381).

Finally, research on service utilization of persons with dementia has proceeded with difficulty due to the complexity of the relationship between informal care and the supplemental use of formal services (Frank et al., 1988). Morycz (1985) found, for example, that for caregivers of people with Alzheimer's disease informal support instrumentally expressed could reduce the likelihood of patient institutionalization through a reduction of caregiver burden. Other studies have been inconclusive, however. A review of the literature on caregiving found that there is some evidence that formal services do not decrease burden, even if provided in the form of respite services for caregivers (Ory et al., 1985). That these two systems, the informal support network and formal services, interact is now accepted in the literature. How they interact, particularly with the Alzheimer's disease population is still unresolved.

While research proceeds on the effectiveness (and cost effectiveness) of formal services in delaying the eventual institutionalization of persons with Alzheimer's disease (Mittleman et al., 1996; 1997), it is equally important to determine why available services are currently underutilized. It is clear, however, that "need" alone is a necessary, but not sufficient, basis for formal service utilization by caregivers of people with Alzheimer's disease. One factor that may influence these decisions is the presence of caregiver stress and burden.

Impacts of Caring for Persons with Alzheimer's Disease and Related Disorders on Informal Caregivers

Perhaps more than any other disease of old age, dementia, especially Alzheimer's disease, affects the family as well as the patient. The terminal nature and unpredictability of the illness as well as the combination of mental decline, loss of independence, and increasing need for supervision and assistance are especially stressful for family caregivers (Vitaliano, Young & Russo, 1991; Dillehay & Sandys, 1990; Pallett, 1990; MaloneBeach, Zarit, & Spore, 1992; Deimling & Bass, 1986; Ory et al., 1985).

Empirical evidence suggests that caregivers experience a variety of significant negative psychological, social, financial, and health consequences related to caregiving including depression, anger, anxiety, guilt; negative attitudes towards the patient and other family members; deterioration of the caregiver's physical health; constraints on the caregiver's social participation; the caregiver's withdrawal from the workforce and/or loss of personal time; increased financial expenditures, increased role conflict and role strain; disruption of other family relationships and routines; and the loss of the relations with the impaired elder (cf., Zarit, 1992; Cafferata & Stone, 1989; Anthony-Bergstone, Zarit, & Gatz, 1988; Deimling et al., 1989; George & Gwyther, 1986; Pruchno & Resch, 1989; Gallagher, et al., 1989; Stone et al., 1987; Zarit, Reever, & Bach-Peterson, 1980). These negative effects are typically referred to as caregiving burdens. Although it is generally agreed that being a family caregiver can be very stressful, there are marked individual differences in the degree to which family caregivers experience these negative consequences (Zarit, 1992; Dillehay & Sandys, 1990), and the relationship between patient characteristics, behaviors, and symptoms, caregiver characteristics and negative caregiver outcomes is not yet clear (Kulhman et al., 1991; Harper & Lund, 1990; Vitaliano et al., 1991).

The predominant theoretical model used in the caregiving literature is the stress process framework. This framework views stress in three distinct components: stressors (e.g., the nature of the care receiver's illness, objective life events, chronic strains, etc.), mediators (primarily coping behaviors and social support), and outcomes (psychological distress) (cf., Pearlin et al., 1994, 1990, 1989; Stephens & Zarit, 1989; House, Umberson, & Landis, 1988; Lazarus & Folkman, 1984; Thompson, et al., 1993). The key components of the stress process model are considered dynamically related such that a change in one is potentially capable of producing change in other components over time. Additionally, it is assumed that stressors beget other stressors because different areas and roles of people's lives are interconnected and as a result, problems in one area can potentially affect others. Thus, the constellation of stressors is an important part of understanding variability in outcome measures (Pearlin, 1994).

Although the concept of caregiver burden or psychosocial distress has been the central outcome measure utilized in stress research, this literature has demonstrated wide variation in the conceptualization, labeling and measurement of these effects (Deimling, 1994; Braithwaite, 1992; Kahana, Kahana, Johnson, Hammond, & Kercher, 1994). For example, early conceptualizations of burden involved multidetermined strain or discomfort aroused by the responsibilities of caregiving (Thompson et al., 1993). Efforts to develop more refined operationalizations of the process by which caregivers become burdened led researchers to distinguish between the events, happenings, and activities associated with negative caregiving experiences (i.e., the objective measures of burden) from the feelings, attitudes, and emotions of the caregiver in response to caregiving duties (i.e., the subjective measures of burden) (George & Gwyther, 1986; Horowitz, 1985; Montgomery, Gonyea, & Hooyman, 1985; Montgomery, Stull, & Borgatta, 1985; Poulshock & Deimling, 1984; Thompson and Doll, 1982).

Research suggests that providing care for person's with Alzheimer's disease can exact a psychological and physical toll on caregivers (Zarit et al., 1980; Hirschfeld, 1979; Mace et al., 1980; Zarit et al., 1980; Levine et al., 1983; Greene et al., 1982; Gilhooly, 1984; Ory et al., 1985; Morycz, 1985; Farkas, 1980; Rabins et al., 1982; Thompson and Doll, 1982; Robinson 1983; Johnson and Catalano, 1983; Poulshock and Deimling, 1984; Gilhooly, 1984; Niederehe and Fruge, 1984; Aronson et al., 1984; Montgomery et al., 1985; Morycz, 1985; Deimling and Bass, 1986; Fitting et al., 1986; Scott et al., 1986; Chenowith and Spencer, 1986; Moritz et al., 1989; Lawton et al., 1989a; Kinney and Stephens, 1989; Novak and Guest, 1989; Pearlin 1990; Vitaliano et al., 1991a; 1991b; Gallagher; 1985; Horowitz, 1985; George and Gwyther, 1986; Haley et al., 1987a; 1987b; Callahan, 1989; Brody and Saperstein, 1989; Lawton et al., 1989b; Miller and McFall; 1991; 1992; Miller et al., 1991; Braithwaite, 1992). Reductions in the health status of caregivers have been widely described (Sainsbury and Grad de Alarcon, 1970; Arcibold,

1982; Farkas, 1980; Barnes et al., 1981; Haley et al., 1987) as have changes in mental health status, especially related to depression (Eagles et al., 1987; Gilhooly, 1984; Moritz et al., 1989).

In one study (Cohen and Eisdorfer, 1988) 55 percent of a sample of caregivers who did not participate in support groups or have access to respite care experienced clinical levels of depression. Studies show that approximately 49 percent of female caregivers and 31 percent of male caregivers experience depression as a result of caregiving. Among spouse caregivers, 21 to 25 percent of husbands and 50 to 52 percent of wives are depressed (Gallagher et al., 1989; Cohen et al., 1990). Caregivers use prescription drugs for depression, anxiety, and insomnia two to three times as often as the rest of the population (George & Gwyther, 1986). Notwithstanding the potential ill-effects caregiving can impose on family caregivers, caregiver stress and burden have indirect policy relevance because of their association to the family's decision to relinquish the caregiving role and institutionalize the care recipient (Braithewaite, 1992).

Studies have also documented decrements among caregivers in life satisfaction, well-being or similar constructs (Gilhooly, 1984). A number of studies have documented the subjective experience of burden in caregivers (Zarit et al., 1980; Zarit et al., 1986; Wilder et al., 1983; Cantor, 1983), while other studies have identified family conflicts that have been associated with caring for a demented person (Niederehe and Fruge, 1984; Wilder et al., 1983; Rabins et al., 1982). There is also evidence to suggest that female caregivers experience greater negative mental health impacts (Fitting et al., 1986; McKinley and Tennistedt, 1986) while other investigators report no gender differences (Robinson, 1983; Zarit, Reever and Bach-Peterson, 1986). Based on a community sample of spouses who live with cognitively impaired elderly persons, Moritz et al. (1989) report that husbands evidenced more depressive symptomatology than wives as a function of the patient's level of cognitive impairment. Research regarding the relationship between caregiver characteristics (such as caregiver age, gender, education, employment status, relationship and proximity to the patient, etc.) and caregiver outcomes is also inconsistent.

For example, gender differences are believed to influence the amount and type of care provided, access to social resources that may alleviate caregiver strains, and appraisal of the caregiving experience (Pearlin et al., 1990; Miller & Cafasso, 1992). The research so far has shown sex differences appearing in some studies but not in others. Pratt et al., (1985) examined the caregiver's sex, age, income, education, patient residence, presence of confident relationship, and membership in a support group to caregiver outcomes and found no relationship between these caregiver characteristics and burden, although burden scores were significantly lower for caregiver's reporting their health as excellent or good versus those reporting their health as fair or poor. Alternatively, Cafferata and Stone (1989), using indices of objective and subjective burden in an examination of the caregiver role, found that variations in burden were associated with both patient and caregiver characteristics. Total subjective burden, role strain, and role conflict were related to caregiver age, gender, health status, living with the patient, those receiving support services, caregiver's work status as well as to the patient's level of physical impairment and the difficulty of the caregiving task. Perceived burden was higher among females than males and among caregivers in "fair or poor" health than among others. All types of burden were higher among persons who left work to care for the patient than among caregivers who still worked or were retired. Finally, role conflict was related primarily to the caregiver's gender, with females reporting more role conflict than males, while role strain was related to nearly every caregiver characteristic identified, including age and race (higher for older caregivers and higher for whites than nonwhites).

While most caregivers are wives and daughters, males form a relatively large proportion of caregivers when only those with major responsibility for care are considered (Malone Beach & Zarit, 1991). However, the type of caregiving provided by men is reported to be qualitatively different from that provided by women (Parks & Puilisuk, 1991; Stone et al., 1987). Based on the research on caregiving to date, women offer significantly higher levels of overall assistance than

men, they are much more likely than males to attend to the personal hygiene needs of the care recipient and to engage in household tasks and meal preparation.

Spouses of persons with Alzheimer's disease appear to be at greatest risk of burden for they often are elderly themselves and may have physical problems that would decrease their capacity to respond to the demands of caregiving (Barusch, 1988; Pruchno & Resch, 1989; Fitting et al., 1986), although spouses often demonstrate equivalent or better emotional adjustment to the caregiving situation than adult children (George & Gwyther, 1986; Jenkins, Parham, & Jenkins, 1985). There is some evidence that men and women may be equally affected by stressors but each may express the effects in different ways (Aneshensel, Rutter, & Lackenbruch, 1991). For example, women appear to be predisposed to manifest stress in depression while men tend to manifest stress in excessive drinking and aggressive behavior (Pearlin & Zarit, 1993). Pruchno and Potashnik (1989) found that spouse caregivers were more depressed, less satisfied with their lives, more likely to use psychotropic drugs, and more likely to report symptoms of psychological distress as well as higher rates of diabetes, arthritis, ulcers, and anemia than were community dwelling elderly people who were not caregivers.

Recent critiques of the caregiving literature suggest that findings about gender differences in care may be subject to sample bias from an over reliance on small, clinically drawn samples, lack of consistent measures of key concepts, and an emphasis on statistically significant gender differences while ignoring findings of no difference (Abel, 1990; Barer & Johnson, 1990). Miller and Cafasso (1992), in their critique of the caregiving research literature, state that the findings of significance often occur among a series of significance tests which increases the likelihood that the significant findings occurred by chance and that the practical and clinical implications of the size of the gender differences found are often minimalized. Thus, not only is the probability of a Type I (false positive) error increased, the meaning of "findings of no gender differences tend to be ignored" (p. 498). In a meta-analysis of 14 descriptive studies of gender differences in caregiving, they found that there were essentially no significant gender differences in functional impairment of the frail care recipient or total caregiver involvement in care.

Cattanach and Kraemer Tebes (1991) assessed the relative impact of elder impairment on the health and psychosocial functioning of caregiving daughters and daughters-in-law to different types of impaired elders. Contrary to expectations, caregivers of cognitively impaired elders, functionally impaired elders, and non impaired elders did not differ on measures of psychological distress, depressive symptomatology, physical symptoms, number of hospital visits, number of physician visits, or number of days sick in bed. In terms of psychosocial measures, there were no significant differences among the groups in incidence of negative life events, level of perceived stress, approach to coping, other perceptions of social support or perceived control. Only one significant difference among caregiver groups was observed; caregivers of non impaired elders reported significantly more tangible support than caregivers of functionally impaired elders. Because of these discrepant findings, no clear statement can be made regarding the effects of gender on caregiver impacts.

Investigators have also examined the consequences for caregivers of stresses and strains associated with providing care. Financial problems have been identified as having an impact on caregiver well being and levels of depression (Cantor, 1983; Ory et al., 1985; Thompson and Doll, 1982; Moritz et al., 1989). There is also evidence to suggest that reductions in employment outside of the home can be another result of caregiving (Brody, 1985). There is general agreement, however, that accessible social support mitigates negative impacts associated with caregiving (George and Gwyther, 1986; Scott et al., 1986).

Social support is thought to buffer or mediate an individual's response to stressful situations (cf., Pearlin et al., 1990) and has been associated with effective coping styles (Parks & Pilisuk, 1991; Scott et al. , 1986; Pratt et al., 1985) and with lower levels of depression (Fiore, Becker, &

Coppel, 1983). However, there is little conceptual clarity concerning what elements constitute social support and the overlapping components that have been studied confound interpretations of the research conducted so far (Thompson, et al., 1994; Dillehay & Sandys, 1990).

Social support is often operationalized in structural terms, such as the number of people within a network the caregiver can turn to (e.g., Vitaliano et al., 1991), or in functional terms, such as tallying the number of caregiving tasks for which informal helpers gave assistance (e.g., Lawton et al., 1991), or as social integration/lack of support as measured by indexing the number of helpers who assist the primary caregiver (e.g., Bass, Tausig, & Noelker, 1988). The most commonly used measures of support focus on some rudimentary indication of whether caregivers are participating in support groups, whether they receive family visits in a specified period of time, or a judgment by the caregiver about the adequacy of help received (Dillehay & Sandys, 1990; Pearlin et al., 1990).

Investigators have further attempted to examine levels of caregiver impact associated with particular patient characteristics such as cognitive impairments, functional impairments, and problematic behaviors. Studies that have examined the relationship between patient functional impairments and caregiver functioning have demonstrated positive relationships (Deimling and Bass, 1986; Poulshock and Deimling, 1984; Wilder, Teresi and Benett, 1983), but other studies have indicated, for example, that functional impairment in the wife does not account for increased depression scores in the husband (Moritz et al., 1989). Other studies have found that cognitive functioning, but not ADL scores, predicted subsequent institutionalization (Fisk and Pannill, 1987; Colerick and George, 1986). Research on whether patient characteristics such as age, patient health, functional or cognitive status, and problematic behaviors, are, in and of themselves, important factors in caregiver well-being and burden remain equivocal. A number of studies have shown that caregivers of functionally impaired elderly people are more likely to report health problems than caregivers of functionally intact elders (Silliman & Sternberg, 1988) and that caregivers of elderly people requiring greater assistance with ADLs are more likely to report disruptions in health than caregivers of elderly requiring less care (Horowitz, 1985). Studies that included persons providing care to psychiatric patients (Pearson, Verma, & Nellett, 1988) or to heterogeneous samples of impaired elderly (Pruchno & Resch, 1989; Deimling & Bass, 1986; Montgomery, Fengler & Goodrich, 1979), found a positive relationship between degree of stressor (e.g., patient functional status, disruptive behaviors, patient symptoms) and caregiver outcome (e.g., depression, burden). Thompson et al., (1993) examined a variety of patient characteristics in relation to five measures of caregiver burden (e.g., patient age, gender, patient ADL task dependencies) in 217 family caregivers of frail elderly (including dementia patients). Patient task-dependency was significantly correlated to three of the five burden measures (a global measure of burden, indexes of how tiring, difficult and upsetting responsibilities to assist in ADL's were to the caregiver, and constriction of the caregiver's social life).

However, Zarit, Reever, & Bach-Peterson, (1980) examined patient characteristics, including patient cognitive impairment, memory and behavior problems, patient functional abilities, duration of illness, and frequency of family visits on caregiver outcomes. The only factor related to caregiver burden was frequency of family visits. Harper and Lund, (1990), in a study examining the relationship between burden, living arrangements and type of caregiver, found that burden scores were consistently higher among the caregivers who lived with the patient, followed by those where the patient lived in a nursing home, followed by those where the patient lived elsewhere in the community. They also found that symptoms such as aggression and/or changes in personality were especially stressful for women, regardless of their proximity to the patient (e.g., living with the patient, patient living in another setting, etc.). This is supported by similar findings that strains associated with mental dysfunction and disruptive behaviors had a stronger impact on the quality of the caregiver relationship than did the demand of physical care (Zarit et al., 1982; Deimling & Bass, 1986).

The most consistent patient characteristic related to caregiver burden appears to be patient cognitive impairment and/or behavior problems. Indeed, frequency and intensity of patient memory and behavior problems have not only been associated with increased caregiver burden, they have been associated with the caregiver's decision to institutionalize the patient as well (cf., Cohen, et al., 1993; Hamel et al., 1990). Zarit et al., (1986) found that the greater the frequency of patient memory and behavior problems and the greater the caregiver intolerance of these problems, the greater the burden. Fitting et al., (1986) and Morycz (1985) also found burden associated with increased patient severity of illness. Fitting et al., in a study comparing husbands and wives, found that men and women experienced similar degrees of burden but wives reported more depressive symptoms. Further, they found that burden increased with severity of the illness for younger wives and older husbands but not for other age groups and that severity of dementia did not affect depression scores in husbands but did affect depression in wives. Nevertheless, both Fitting and Zarit found that these relationships between burden and problem severity were dependent on the age and sex of the caregiver.

Hamel et al., (1990) examined the frequency, nature, and context of aggressive behavior in dementia patients and caregivers' reactions in order to predict the extent of aggression, caregiver burden and plans for institutionalization in a sample of 213 caregivers and care receivers. Higher burden scores were associated with caregivers who reported themselves less healthy, who had poor social interactions with the patient prior to onset of the illness, who were caring for patients with a greater number of behavior and memory problems, and who reported themselves more distressed by the patient's behavior problems. Furthermore, caregivers who were not spouses, were less healthy, had higher incomes, reported more burden and use of formal services, and were caring for more aggressive patients who exhibited more memory and behavior problems were more likely to report planning to institutionalize the dementia patient.

Deimling and Bass (1986) examined patient mental impairment along three dimensions: deterioration of cognitive abilities, problems in level of functioning (ADLs/IADLs), and the occurrence of disruptive behaviors. Results from their study of 614 families living with an Alzheimer's patient showed that cognitive impairment was less of a stressor than either disruptive behaviors or impaired social functioning. In a similar vein, Pruchno and Resch (1989), investigated elements of problem behaviors, their trajectory over time, and caregiver adaptation. Findings suggested a relationship between caregiver well-being and the frequency of forgetful, asocial, and disoriented patient behaviors, although the relationship is complex. Asocial and disoriented behaviors were related to burden, certain specific consequences of caregiving and lifestyle change in a linear manner. The more frequent the asocial or disoriented behavior, the more stress experienced by the caregiver. It is the unpredictability and the social unacceptability of the behaviors that is stress-provoking. The lack of a relationship between forgetful and disoriented behaviors and depression suggests that caregivers find these behaviors annoying and problematic but they do not necessarily affect their lives in the same way that aberrant asocial behaviors do. Thus, burden does not necessarily follow a linear trajectory with functional/behavioral impairments but may peak in the middle phases of AD when behavioral problems are the most evident and problematic (Vitaliano et al., 1991). Generally speaking, patient characteristics have an effect on caregiver reports of subjective burden, but the contribution of different patient characteristics on caregivers is still questionable.

Demonstration Goals and Program Design

This demonstration provides an important opportunity to assess many issues related to the effectiveness, cost, and impact on both patients and caregivers of the provision of a wide array of services for persons with Alzheimer's disease and related disorders. The demonstration is designed to address two of the major difficulties encountered by caregivers. First, the need for community-based services that are geared toward meeting the care needs of demented persons. Second, because of the long term care coverage limitations of the Medicare and Medicaid

programs, the creation of reimbursement schemes that will increase access to these services. The demonstration addresses these two needs by providing sites the flexibility to deliver a number of community-based services oriented toward persons with Alzheimer's disease or a related dementia through a case managed system approach, and by providing reimbursement for services that are not normally available under regular Medicare or Medicaid reimbursement schemes.

Because of limitations in Medicare coverage of long term care for people with chronic dementing disorders, coupled with the variable patchwork system of long term care services available in states through Medicaid or Medicaid waiver programs, Congress established the Medicare Alzheimer's Disease Demonstration through section 9342 of the Omnibus Reconciliation Act of 1986 (OBRA-86). Section 4164(a)(2) of the the Omnibus Reconciliation Act of 1990 (OBRA-90) extended the demonstration an additional year from the original three years specified in OBRA-86. The broad goal of the demonstration is to assess the effect on demented persons and their caregivers of increased access to an expanded range of Medicare-funded community-based long term care services. The basic goals of the demonstration were fourfold and included: (1) ensuring the development of an effective network of community-based services that address the medical, mental health, and social support needs of persons with Alzheimer's disease and related disorders and their caregivers; (2) providing education and support services to caregivers to minimize stress associated with caregiving and to enhance caregiving skills; (3) creating opportunities for demented persons to be cared for in preferred, protective home-like environments and supporting use of the most appropriate level of care whether in institutional or community settings and; (4) insuring that the services provided are cost-effective and that the costs of care are equitably distributed. Within these broad goals, demonstration sites sought to: 1) provide a range of affordable, high quality community services; 2) provide information and assistance to clients and caregivers that will allow them to access these services by arranging and paying for a portion of their costs; 3) provide assistance to caregivers to help them cope with caregiving responsibilities and; 4) provide support and assistance to caregivers to make an appropriate decision to institutionalize clients or keep them at home.

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Appendix Two

Demonstration Design and Implementation Issues

Two Models of Care

The demonstration intervention and evaluation was designed by Mathematica Policy Research (MPR) under contract to HCFA. MPR also worked closely with HCFA in developing guidelines for selecting sites, working with the selected sites in the initial stages of implementing the demonstration, assessing the hypothesized impacts of the demonstration (discussed in chapter three), and developing the evaluation contract parameters. The centerpiece of the evaluation developed by MPR is an experimental design wherein participants are randomly assigned to either the treatment group which receives the expanded range of demonstration services and case management, or the control group which receives none of the case management or other services. This type of evaluation design helps to insure that any differences observed between the treatment and control groups can reasonably be attributed to the interventions being tested.

Hypothesized differences between the treatment and control groups were examined in terms of the impact of the demonstration on demented persons, their caregivers, service utilization patterns, and expenditures. Case management services were a centerpiece of the intervention because caregivers of demented persons, especially if the onset of dementia is relatively recent, are expected to have little experience in accessing services that can assist in the provision of care for the client. Because of the relatively low formal social and health service utilization rates of elderly people in general and demented people in particular, aggressive outreach efforts by demonstration sites were necessary to identify those who were eligible to participate in the program.

Criteria for enrollment in the demonstration were that all eligible applicants must have a diagnosis of an irreversible dementia, be enrolled in (or be eligible for) both Parts A and B of the Medicare program, and reside in the demonstration site's catchment area. Medicare beneficiaries were eligible for participation in the demonstration if, in addition to the three criteria, the patient's physician provided information requested on a Physician Referral Form. The information requested on this form included the specific dementia diagnosis(es), whether alcohol was a significant contributing factor to the patient's dementia, information concerning the patient's medical history, medications the patient was currently taking, and results of specific laboratory tests, if available. Applicants who met the criteria and who resided in a nursing home or hospital were eligible to participate in the demonstration if discharged within one month of their application.

A number of conditions were added to both the eligible and ineligible lists of disorders that were not specified in the MPR design. Although many diseases that were added produce dementia in only a small percentage of cases, they were included so as to provide a more refined list of eligible and ineligible disorders (Katzman, Lasker and Bernstein, 1988) to assist community physicians in referring individuals to the demonstration. Because most of the data collected under the demonstration were obtained from the patient's primary informal caregiver, most participants had a source of informal assistance. Patients without an informal caregiver participated in the demonstration if a formal support system had been developed and adequate formal assistance was provided to allow the participant to remain in the community.

Two case management models were tested under the demonstration and provided service delivery variation along two continua: the type of services that are provided (across site variation is due to local service system differences) and the intensity of service provision (variation is due to differences in cost caps between the models). Case management is the centerpiece of both models and the design of the demonstration allows for the provision of services to persons with Alzheimer's disease and related disorders that are not otherwise available or reimbursed by existing mechanisms of community-based long term care service provision. The two models tested vary along two dimensions: the case manager-to-client ratio and the level of the allowable per-month expenditure cap for each client. A comparison of the basic characteristics of the two models is outlined below:

Model A	Model B
Low-Expenditure Cap	*High-Expenditure Cap Model*
1:100 case manager-to-client ratio	1:30 case manager-to-client ratio
Provides in-home services including homemaker/chore, personal care, home health, skilled nursing, as well as other services	Same
Provides medical, social or Alzheimer's-specific adult day care	Same
Other community services	Same
Incorporates an overall "low" cap on per patient expenditures per month	Incorporates an overall "high" cap on per patient expenditures per month

These models were chosen by MPR because case management was seen as a key service component for demented persons and their families. Both models also allow for the provision of a wide range of services, and the differences in case management intensity and service expenditure caps provide a test of models at different funding levels. Demonstration sites were reimbursed for case management at cost, 80 percent for direct services, and 100 percent for direct services if the demonstration participant is also a Medicaid recipient. Except for Medicaid participants, patients and families paid for the remaining 20 percent of service costs. The cost-sharing approach was expected to provide patients and/or families with an incentive for cost consciousness.

The monthly service cap amounts were adjusted for geographical cost variations and ranged from an initial low of $299 per month to a high of $430 per month under the low resource model and a low of $489 per month to a high of $699 per month under the high resource model. The caps were increased incrementally as the Demonstration progressed to account for inflation and other factors. Sites were instructed to use public (e.g., Medicaid, Title XX, Title III) or private (e.g., United Way, Catholic Charities, Jewish Federation) sources of funding for community health and social services prior to the use of demonstration-supported services. Demonstration services could, however, be used to replace or supplement health or social services that clients or their family members pay for out-of-pocket.

The demonstration was designed to pay for a wide variety of community-based long term care services, many of which are reimbursable under the Medicare skilled care benefit. However, under the regular Medicare benefit, skilled in-home services are provided in association with an acute hospitalization episode and are designed to assist the patient in the post-hospitalization recovery period, not to assist in protracted long term care resulting from the effects chronic diseases. The services covered by the demonstration included the following:

- adult day care
- skilled nursing
- rehabilitation nursing
- therapies (i.e., speech, occupational, physical)
- home health aide
- homemaker/personal care
- housekeeping

- general chore (i.e., heavy cleaning)
- home repairs and maintenance
- companion (i.e., friendly visiting, incidental shopping and errands, telephone reassurance)
- companion for education and training (so caregiver can leave home to participate in education/training sessions)
- home delivered meals
- non-emergency transportation for client
- adaptive and assistive equipment
- medical supplies
- durable medical equipment
- consumable care goods
- mental health treatment
- caregiver education and training
- family counseling
- caregiver transportation to support groups
- case management
- medical assessment

A total of eight model sites were selected, four of which operated under Model A criteria and four of which operated under Model B criteria. The sites were located in different geographical regions of the United States and are listed below:

Model A Sites

Monroe County Long Term Care Program, Inc.
Rochester, New York

Carle Clinic Association
Urbana, Illinois

Northeast Community Mental Health Center
Memphis, Tennessee

Good Samaritan Hospital and Medical Center
Portland, Oregon

Model B Sites

Cincinnati Area Senior Services, Inc.
Cincinnati, Ohio

Wood County Senior Citizens Association
Parkersburg, West Virginia

Amherst H. Wilder Foundation
Minneapolis, Minnesota

Miami Jewish Home and Hospital for the Aged
Miami, Florida

The demonstration interventions were conducted for a period of 3 years and demonstration sites either directly provided and/or arranged for the provision of demonstration reimbursed services.

To implement the demonstration in the context of the evaluation design, a number of decisions were made that provided guidelines to the sites for operationalizing the models being tested. Implementation issues arose in client outreach and enrollment and case management model implementation.

CLIENT OUTREACH AND ENROLLMENT

To mitigate against contamination of the evaluation design that may have occurred as a result of procedures necessary to enroll clients into the demonstration, a number of policies were developed to provide site staff with guidelines for enrolling clients. "Contamination" in the context of the demonstration refers to the receipt of services equivalent to those offered through the demonstration. Receipt of such services by the control group would seriously affect the evaluation in that, for all practical purposes, there would be no difference between the services received by the treatment and control groups.

Service Intervention by Intake Interviewers During Enrollment

Client safety, both at the time of the evaluation intake interview and after enrollment into the demonstration, was an important concern of HCFA, the demonstration sites, and the evaluation team. Guidelines were developed in conjunction with HCFA and the sites to insure that client needs in this area were not secondary to the implementation of the demonstration or the evaluation design. Life threatening or other emergency interventions (e.g., elder abuse, protective service, or institutionalization actions) necessary during initial contacts with the client or their families were responded to as appropriate. Any client who required interventions because of safety concerns prior to randomization was deemed ineligible to participate in the demonstration.

The policy that was promulgated regarding interventions in such cases was that client emergency or life threatening situations arising after randomization into the treatment group received whatever assistance was appropriate by either the host demonstration site or through referrals to other agencies. Among the control group, it was possible that referrals for assistance would come through the demonstration host agency and sites were instructed to respond to these requests in their standard practice manner, not using the services of the demonstration or the demonstration case managers.

If, during the intake interview, the interviewer provided assistance to the client or caregiver (e.g., the interviewer assisted the caregiver in cleaning the client after an episode of incontinence), but there was no discussion of where to go for help with the problem and no referrals are made for further outside assistance, then the client remained eligible for participation. If the client or caregiver requested a referral for help, a standardized handout listing the name of the two referral sources identified by the site (i.e., an information and referral agency and the local Alzheimer's Association) was given to them by the interviewer. If in the course of providing assistance to the client or caregiver during the intake interview the interviewer found it necessary to provide information about other service providers in the community beyond that contained in the standardized handout, then the person was no longer eligible for the demonstration.

If an accident or a problem arose during the intake interview that was not an emergency but needed to be resolved before the interview could be completed, the following options were available for the intake interviewer:

- Interviewers could suggest that they would be happy to wait while the caregiver and client take care of the problem; or
- Interviewers could reschedule a time to return and complete the interview.

The critical factor in the intake interviewer's determination of whether an applicant remained eligible for the demonstration was the provision of information about service providers in the

community beyond that available on the standardized handout. If any information beyond the standardized referral handout was provided, then the client was ineligible for the demonstration.

Interviewers were instructed to treat information requests for services received before or after a client was assigned into the control group in a uniform manner. All responses to such requests took the form of the standardized handout listing the names of the two identified referral sources. If information requests were directed to the site from any agency or potential applicant, they were responded to in the site's standard practice manner and did not involve the demonstration case managers. If an applicant exhibited or expressed non-emergency service needs during intake but did not request help, the interviewer did not volunteer referral information. This was a necessary procedure to reduce control group contamination. Sites were also instructed that, if after randomization a control group member/caregiver called the site, the client or caregiver should be treated in the site's standard manner but they remained ineligible for any demonstration services.

Determination of Clients' Unmet Needs

The eligibility criteria for the demonstration specified that clients had to have "unmet needs" to be considered for participation in the demonstration. For the sake of operational simplicity, if the client/caregiver applied to the demonstration and the client's physician completed and returned a physician referral form to the site, these were actions which, in and of themselves, constituted "unmet need" for the demonstration services. With the exception of "rollover" cases defined below, clients were allowed to enroll in the demonstration regardless of the type or level of current formal or informal services. Implicit in this interpretation was the decision that the treatment group did not have to be segregated from the controls if they were receiving non-demonstration services.

Guidelines for Classifying Clients on "Roll-Over" Cases

The concern with "rollover" cases was how to minimize the possible contamination of the control group. "Rollover" cases consisted of: 1) clients who wanted to participate in the demonstration but who potentially were receiving services that equalled or surpassed those that could be obtained from the demonstration if they were randomized into the control group; and 2) clients who did not have either an informal or formal caregiver. Communities with 2176 Medicaid waiver programs were the most frequent source of rollover clients. The 2176 Medicaid Waiver programs provide expanded community-based services to Medicaid eligibles. The services covered under this program vary by state. Efforts to minimize contamination began with the consideration of the question: "What is the purpose of the demonstration, to compare the effectiveness of the case management and waivered reimbursement for services against no case management and no reimbursement for services; or to compare the benefit of the demonstration's reimbursement and case management against the prevailing treatment experience in the community?" Since the latter purpose was deemed appropriate, and sites had no ability to control what happened to the control group or in the community service delivery system, the most effective point in time for minimizing contamination was at enrollment into the study.

To minimize contamination, each site identified programs in their community which were offering case management services comparable to, or more extensive than, those offered by the demonstration. Such programs included Medicaid waiver programs, other federal demonstrations, or certain specialized housing projects such as life care. Residential care housing did not automatically fall into this category. Sites were given the option to categorically exclude from the demonstration everyone receiving services from these types of programs.

For sites that chose not to categorically exclude persons receiving services from programs similar to the demonstration intervention, the site could enroll a maximum number of clients from all of these programs taken together. For sites that chose this option, the total number of allowable

rollover clients in both treatment and control groups was computed based on the total number of "non-rollovers" necessary to statistically detect the effects of the demonstration.

Because it was anticipated that many clients and their caregivers would not know that they were receiving case management services, since the term may be unfamiliar to them, sites were provided a script with appropriate probes so that the determination of a rollover client could reasonably be made. If an applicant was receiving services from a "rollover" program identified by the site, site staff were instructed to call the agency to determine what services were being received by the applicant. If the applicant was receiving case management services similar to the demonstration intervention, then they would be considered a rollover for purposes of the rollover caps established for each site. The judgement as to "potentially" duplicative service providers was left to the case managers at each site because of their detailed knowledge of the structure of services provided in their community.

Within the months of December, January, and February 1989-90, one out of three cases submitted for randomization were allowed to be rollovers, up to a site's maximum number of allowed rollovers. If an applicant was receiving services from one of these identified agencies, site staff called the agency to determine what services were being received by the applicant. If the applicant received case management services similar to the demonstration intervention, then they were considered a rollover for purposes of the rollover caps that were established for each site.

If sites did not reach their rollover caps in the first 3 months of the enrollment period, they continued to randomize rollovers into the demonstration until the caps were reached. If a rollover client left the demonstration for any reason (e.g., death, moved out of the area) after the cap was reached, the client had to be replaced with a non-rollover case. During the course of and after the completion of the demonstration enrollment period, evaluation staff checked on rollover cases to confirm whether they were actually rollover cases. Staff used the following criteria to assess whether a case was a legitimate rollover:

- the case had to be open to case management at the time of the demonstration intake interview;

- The case management being received had to be more than just establishing ongoing eligibility; it must be long-term; and the frequency and intensity of contact must be enough that the client (or more likely, the caregiver) knows the name of the case manager and the case manager would likely be in contact with the client (or caregiver) when assistance was needed;

A small percentage were found not to be rollovers and were taken out of that category for purposes of characterizing the enrolled sample. The rollover caps were established to ensure an adequate number of non-contaminated cases at each site. The goal was to enroll no more than 15 percent of the study sample and no site reached its maximum number of allowable rollover cases.

Diagnosis of Dementia

Clients were deemed eligible for the demonstration if their physician attested to the fact that the client had an irreversible dementia. A requirement to obtain a differential diagnosis of dementia as a condition for participation was considered but was deemed to be problematic both in terms of time and cost. With regard to cost, for example, if all of the approximately 8,000 people enrolled in the demonstration were given a comprehensive diagnostic work-up to determine eligibility, the cost would have been approximately $8 million or 20 percent of the original congressional appropriation for the entire service portion of the demonstration (assuming a conservative cost of $1,000 per client per work-up). Time limitations also would have made it impossible to complete diagnostic work-ups on all clients. For example, across California's nine specialized Alzheimer's

Disease Diagnostic and Treatment Centers (ADDTCs) an average of 900 patients are assessed per year. Even if clinical facilities located in the communities of the eight sites could complete three times as many diagnostic work-ups per year than ADDTCs (i.e., 2,700 clients evaluated across all sites per year), it would still have taken over two years just to diagnose everyone enrolled in the demonstration. This also does not include finding cases. Because of these constraining factors, HCFA and the evaluators chose to rely on the patient's physician's judgments. At their request, sites were provided with the following guidelines for a diagnostic work-up to distinguish a reversible from an irreversible dementia. The required steps (estimated to cost between $1,500 and $2,000) to make this differentiation were as follows:

- A comprehensive history and physical
- Mental status examinations including tests such as the MMSE, a verbal fluency test, and the Blessed Orientation Concentration Test
- A DSM-III criteria checklist for depressive symptomatology such as is available on the Diagnostic Interview Schedule
- A comprehensive neurological examination
- A complete blood screen including B12 and VDRL
- An imaging procedure such as a Computerized Axial Tomography scan to detect treatable silent brain tumors or reversible hydrocephalus.

During the implementation of the demonstration, a question arose from the sites regarding how a diagnosis of "non-specific" dementia should be handled in determining eligibility for the demonstration. Since a major consideration in evaluating the eligibility of an applicant was whether the referring physician had concluded that the client had an irreversible dementia, it was not essential that they classify the dementia into the various eligible diagnoses provided to them as part of the physician's referral form. Questions also arose about situations where a patient has, for example, an Alzheimer's disease diagnosis (an eligible disorder) in conjunction with alcoholic dementia (an ineligible disorder). The policy was that as long as an irreversible dementia diagnosis is included in the physician's assessment, the client is eligible to participate in the demonstration. If a client is later found to have a reversible dementia during the course of the demonstration, the client would be terminated from the study and replaced in the sample.

Changes in Client Status

A number of guidelines were developed to provide information to sites regarding how to handle clients who change status (e.g., death, institutionalization) during the demonstration. Figure 5-1 outlines the follow-up procedures for treatment group clients who had a change of status during the demonstration. This table addresses a broad range of follow-up procedures for clients who had a status change during the course of the demonstration. Included in the table are procedures for treatment group clients who either die, enter a hospital or nursing home, are found to have a reversible dementia, do not pay the coinsurance, fail to comply with demonstration services, etc.

Use of Demonstration Clients in Other Research

The use of demonstration study subjects in other research projects was guided by the following policies: 1) the evaluation data will not be released until the end of the evaluation and then only with HCFA approval; 2) sites can use their own assessment data or other data as long as the use of

these data were non-obtrusive to the clients; and 3) no outside research be initiated that might impact on the time, energy or cooperation of the study subjects or their family members.

Case Management Model Implementation

A major staffing issue arose in the implementation of the evaluation: how to model a full complement of clients for case managers during the client build-up phase. Since client-to-case manager ratios were an important aspect of the demonstration, a method to model full caseload during the period of time it took to achieve full caseload was developed.

The role of case aides and other clerical support to the case managers was a confusing aspect of the demonstration in terms of the delineation of appropriate professional and support roles. Because of the importance of achieving as consistent an implementation of the case management models across sites as possible, sites were provided guidelines to help them delineate the total staff effort allocated for support to the professional roles in case management. Without consistency, there would have been the potential for contamination of the demonstration from the standpoint of the case manager-to-client ratios. The guidelines that were developed included the following case manager roles:

- Case assessment
- Care plan development
- Problem solving and service quality monitoring with the providers
- Problem solving and care plan implementation with the family
- Training of caregivers
- Specifying which referrals are appropriate for the Case Aide to arrange

Counseling services with the patient or family members were expressly excluded as a case management responsibility. These were considered separate services. All other general advice and family support were acceptable case management activities.

To insure the integrity of the models, guidelines were developed for calculating the total amount of case management time that, on average, should be expended per client each month during the client enrollment phase. The time limitations for case managers that were developed for both models were based on a number of straightforward assumptions. First, case managers in Model A sites would have 100 clients at full enrollment while Model B case managers would have 30 clients. Second, case managers under both models would work an average of 40 hours per week. The time guidelines were based on a calculation of the average amount of time per client a case manager would expend at full enrollment under each model. Case manager activities that were not included as part of the time limitations were:

- outreach activities for purposes of caseload build-up
- administrative or other tasks that were not concerned with case

  management, but that were done so as not to exceed the average case manager-to-client time limitations established for purposes of modeling a "steady-state" program
- client assessment activities up to the point where the case manager

reaches 50 percent of full caseload

- activities engaged in by case managers that are a separate billable service.

In the Miami site, the case management model utilized a unit with five Care Coordinators and one RN Consultant. The Care Coordinators maintained an active caseload and the RN consultant has specific responsibilities (assessment, care planning consultation and patient education) for all patients in the unit. The Miami site client to case manager ratio was 1:30, but case managers had caseloads of 36, and the RN worked with all the case managers caseloads to achieve the 1:30 ratio. The time of the RN Consultant was considered as case manager time although spread across a larger number of clients.

A five percent variance above or below the target client-to-case manager ratios was also set. For Model A sites the average variance per case manager at full enrollment using the guidelines was between 95 and 105 cases. For Model B sites the variance ranged from 28 to 32 clients per case manager at full enrollment. To monitor the client-to-case manager ratios at each site, sites submitted a monthly report that included data on the average number of clients per case manager per day. This average number was calculated by adding the per-day case manager caseload by the number of working days in the month (including holidays, vacation and sick leave).

Since a major goal of the evaluation is to understand how the models would operate if they were part of a regular Medicare benefit, measures of client and caregiver outcomes in relation to each intervention necessitated that the programs attempt to operate in as close to "steady-state" as possible. The rationale for setting the time targets was for sites to begin operating as if at full enrollment as early in the demonstration as possible. If this was ignored, then the effects of the two models on the entire caseload would be difficult to assess because clients enrolled early in the demonstration would be receiving case management services under a lower case manager-to-client ratio than those enrolled later in the demonstration. The degree to which site case managers conformed to these guidelines is discussed in Chapter Three.

The average time-per-client constraints that were set were most difficult for the Model A case managers. The extremely limited amount of time case managers had available to deal with client and caregiver problems was a major service delivery constraint for the sites. In the 1:100 model, case managers were instructed to spend an average of 1.5 hours per active case per month. In the 1:30 model, case managers were instructed to spend an average of 5.3 hours per active case per month. These guidelines did not mean that case managers had to spend 1.5 hours (Model A) or 5.3 hours (Model B) on each client per month. Some clients required very little time while others required significant amounts. The goal was for case managers to spend no more than a total of 1.5 hours (Model A) or 5.3 hours (Model B) per enrolled client per month in case management activities.

The constant ratio of case managers to clients was an attempt to maintain the case manager-to-client ratios in both models. As caseloads grew, the total amount of time spent in case management activities increased until case managers were fully occupied in their professional roles. Until full caseload was reached, case managers were instructed to devote their time to other important non-case management activities, such as outreach, to enroll clients.

Guidelines were also developed for case aides which were used in the Model A sites. Sites were instructed to have one FTE case aide to provide case managers with assistance for each 150 clients enrolled at a site. A constant ratio of case aide to clients was developed to facilitate the effectiveness of the planned ratio of case managers to clients in both the Model A and Model B sites. The average case aide-to-client ratio was 30 minutes per case per week. As with case managers, this did not mean that case aides had to spend 30 minutes on each client per week. The goal was for case aides to spend no more than a total amount of time per week in case management

support activities of 30 minutes multiplied by the number of enrolled clients. This limitation only referred to the time a case aide spends assisting the case manager. Case aides could do other types of activities if there were more case aides hired at a site than the 1:150 case manager-to-clients ratio.

Case aides were not required for Model B sites. With their lower client-to-case manager ratios, Model B site case managers did not necessarily need additional help from case aides. Unlike Model A sites with a much higher caseload, Model B site case managers were able to spend a significantly greater proportion of their time working directly with clients. In Model B sites located in service resource rich areas, case managers were concerned that too many professionals would be visiting, thereby potentially increasing stress on the caregiver. Because of this, the case aide time guidelines that were developed outlined the upper limit for FTE case aides per site. So as to not overly constrict the activities of case managers, each site was responsible for determining whether case aides were needed. If they were used, sites were directed not to exceed the established FTE limits during the client enrollment phase to help insure the integrity of the models until full caseload was reached.

The client enrollment phase represented a significantly different situation than at full caseload given the number of new clients that had to be assessed and processed per month. Because of the need to enroll an entire caseload as quickly as possible to fit into the timeline of the demonstration, sites were instructed to exclude the time required to conduct comprehensive assessments from the average time-per-client allocation guidelines for case managers until a case manager had one-half of their caseload (i.e., 50 clients in Model A and 15 in Model B).

Minimum Case Management Data and Delineation of Basic Client Assessment

Guidelines were developed for minimum information standards across the major case management assessment domains. Sites were free to add other items of information in order to tailor assessment and care/action plan activities to the needs of clientele.

In addition to the data included on the evaluation application, physician referral, intake and HCFA fiscal reporting forms, the list of minimum client assessment/case management data that the sites were instructed to maintain on a client-by-client basis appear below:

- Client ID number
- Client name
- Caregiver name
- Date of randomization
- Date of case management assessment
- Location of case management assessment (e.g., home, office, etc.)
- Date case management initiated
- Client and caregiver reported problems and needs (from the assessment form)
- Case manager's perception of client and caregiver's problems and needs
- Plan of action to address identified problems

- Time frames for the implementation of the action plans
- Goals and objectives of planned interventions
- Service information for clients and caregivers
- Medicare and Medicaid client certification/recertification (date of encounters)
- Standard 6, 12, 18, and 24-month reassessments (date of encounters)
- Supplemental reassessments for clients at less than the standard 6, 12, 18, and 24-month intervals (date of encounters)
- Service monitoring and follow-up including date of encounter; initiator of encounter (i.e., case manager, case aide, caregiver, client, other: specify); reason for encounter (i.e., routine follow-up, provider problem, medical emergency, other: specify); and, whether there was a change in the clients' care plan (i.e., yes or no)
- Training and education activities (specify type and duration of training education

Given the difference between the models in terms of client-to-case manager ratios, the specific data and mode of assessment that case managers used was up to each of the sites. The delineation of basic assessment areas important to consider during a comprehensive case management assessment was developed in consultation with the site directors. The sites were given the responsibility to determine what information was important for their case managers to collect in the broad areas of demographic, support system, home environment, health history, functional, psychiatric/behavioral, legal/protective, and formal service utilization. The evaluation team's concern was that all sites were assessing clients in these broad areas, as these are seen as essential to adequate case management and care planning.

Technical Assistance in Implementation of the Case Management Models

As part of the evaluation contract, technical assistance was provided to sites primarily in the area of the implementation of the case management models. Case management for people with Alzheimer's disease is a relatively new professional specialty. As the demonstration began, it was anticipated many sites would not be able to hire staff with training and/or experience in this area. Thus, a plan was made at the outset to contact each of the sites in order to determine if there were any training or informational needs that could not be met on site.

A telephone survey revealed a wide range in the level of need for staff training. Sites also identified training and information needs for caregivers and in-home support staff who would be providing direct services to clients. Some of these unmet training needs were shared across sites. One need many of the sites had in common was a better understanding of the administration and justification for use of certain scales used in the intake instrument - specifically the caregiver stress and burden scale, the depression scale, and the Mini-Mental Status Examination (MMSE). Background information on the reliability and validity of these scales, as well as scoring and administration methods, was mailed to all of the sites.

In addition, there were many requests for further information on specific topics. These requests fell into two major categories: a) information regarding Alzheimer's disease symptoms and behaviors and appropriate interventions for handling these; and b) guides and procedures regarding

the process of case management. Requests for assistance in this latter category came from all the Model A sites as they began to assess the difficulties of providing case management services to clients with one case manager for every 100 clients. It was concluded from this initial survey that there was an urgent need for a training and technical assistance meeting for the Model A sites.

The training was held on April 10 through April 12, 1990 in Baltimore, Maryland. Prior to the meeting, sites sent samples of their assessment tools for the evaluation team to review. Packets of information were prepared for distribution at the meeting containing a review of community-based long term care experiments to date, some resources for caregivers, an in-house review of basic principles of case management as well as a bibliography of articles that dealt with case management, Alzheimer's disease, or both. However, the most important outcome of the meeting was agreement about certain basic domains that had to be covered in some fashion by all case managers during client/caregiver assessment. These included: 1) demographic information; 2) assessment of support systems; 3) environmental assessment; 4) client health history; 5) client functional assessment; 6) behavioral assessment; 7) legal, financial, and protective service issues; and 8) assessment of the use of formal services.

The evaluation team began to receive calls from case managers as the process of randomization began. The majority of these calls were from Model A sites as case managers struggled to define the parameters of a less intensive model of case management, i.e., 1 case manager for 100 clients. Site visits by the training and technical assistance coordinator were conducted to help resolve some of the issues arising at the sites. These visits were completed by May 1990.

Among the many issues discussed at these site visits were: 1) elements that needed to be included in a care plan; 2) the most effective way to make use of nursing staff with expertise in geriatrics; 3) how case managers could provide support for clients and caregivers without finding themselves in a professional "counseling" role; 4) the possibility of using (and how should the project define) "independent contractors" as service providers for the clients; and 5) how to deal with a multi-lingual, multi-ethnic client and service provider mix.

At each site plans were also reviewed for establishing caregiver education, training, and support groups and sites were invited to submit especially difficult or demanding cases for discussion and consultation. The sites also expressed a desire to have a training and technical assistance meeting with all sites represented (rather than by model) to learn from each other and share problems with (and sometimes successful techniques for) training and retraining in-home providers (usually personal care), attracting caregivers to educational support groups, and managing crises effectively.

The Model B case manager technical assistance meeting was held in Baltimore on June 13, 1990. Again, an informational packet was prepared and distributed at the meeting. Many of the problems uncovered at the site visits were discussed at this time and sites shared their methods of resolving them. Among items discussed were: 1) ways of using leverage to obtain the best services for demonstration clients; 2) identifying barriers to service utilization; 3) alternative ways of training and supporting caregivers; 4) the appropriate use of medical, psychiatric, legal and pharmacological consultants; and 5) defining what was expected by the evaluation team in terms of case documentation.

Another technical assistance meeting for both Model A and Model B sites was held in Baltimore on March 26 and 27, 1991. It was held in response to requests from the sites that new problems were occurring in implementing both models as sites reached full projected enrollment. In addition, as a result of staff turnover, many new case management staff had been hired who had not been on board and able to attend previous training. This meeting covered topics such as: 1) the reasons for underutilization of services by caregivers (especially mental health services), and a discussion of how case managers could attempt to deal with this issue; 2) identifying and dealing with elder

abuse and neglect including emotional, physical, and financial abuse; and 3) methods of working with families to avoid unnecessary or premature institutionalization of clients. Many site-specific issues around implementing the model were also covered at this meeting. A packet was prepared with articles and other materials for the sites.

This meeting was followed by a request from the West Virginia and Oregon sites for further assistance. A site visit was made to Wheeling, West Virginia directly following the meeting in Baltimore. One of the main issues dealt with was the appropriateness of the demonstration for treatment of extremely physically ill clients. As the demonstration was "aging," so were many of the original clients and the Wheeling site had several caseloads with a high number of clients requiring intense levels of skilled nursing in order to remain at home. The responsibilities as well as the limitations of the demonstration were reviewed. As client needs became more intense and complex, greater responsibilities and the need for excellent clinical judgment were beginning to become a necessity for case managers. Ways to upgrade the skills of current staff were discussed as well as the need for ongoing staff training and effective use of consultants and available educational resources in the area.

Later in the month a site visit was made to Portland, Oregon. Portland had an almost entirely new staff since the inception of the program. Understandably, they had many questions about implementing the 1-to-100 model and the focus of the day was how to inform, support, and empower caregivers as the case manager-to-client caseload ratio reached the 1-to-100 objective. The assessment procedure had been revamped and streamlined and it was re-reviewed by the training and technical assistance coordinator during this site visit in order to determine if the essential assessment domains were still being adequately addressed.

Another aspect of the training and technical assistance portion of the demonstration was random chart reviews that were completed in July 1990. Each site sent in two to four charts, randomly identified by site and client identification numbers, for review. The training and technical assistance coordinator then reviewed the charts as one method of assessing quality assurance during the implementation of the case management models. The following criteria were used to determine if the demonstration minimum case management standards were being met:

- clear definition of the presenting problem
- adequacy and appropriateness of the care plan
- the timeliness of the implementation of the service plan
- evidence in the chart of regular phone and/or in-home care monitoring of service providers
- the effectiveness of the problem-solving techniques employed
- evidence of a process for determining if case objectives were being met in a timely fashion
- the organization and completeness of the documentation

The intensity and the time spent on individual cases varied by model type but overall it was clear that all sites were effectively meeting at least minimum, and at best very high, standards for case management with this extremely challenging and difficult group of clients. Written feedback on each chart submitted for review was supplied to all sites in a 25-page document prepared by the training and technical assistance coordinator. The quality of case management intervention, the documentation, and the organization of the chart were all reviewed and included in the case-by-case

commentary. Sites were invited to respond with comments and questions on this process, and they in general relayed that they felt it to be a positive learning experience.

The final training and technical assistance meeting was held on April 27-28, 1992 in Cincinnati, Ohio. This meeting included case managers from both Model A and B sites. Topics covered during this training included methods to keep people with dementia out of institutions, maximizing appropriate use of demonstration services, the appropriate use of support groups, and issues surrounding the demonstration wind-down and the integration of treatment group clients back into the normal community service system.

Other training and technical assistance activities have included the following:

- All calls verifying the status of clients who are possibly receiving case management from another source were completed by the training and technical assistance coordinator. At the beginning of this process, criteria (outlined above) were established for what constituted a roughly equivalent form of case management to that provided by the demonstration. These criteria were then used to assign cases to "rollover" or "non-rollover categories."

- The development of appropriate criteria for the use of liquid nutritional supplements with Alzheimer's clients. Two types of indicators (medical and environmental) were developed to assist in identifying a situation where the use of a liquid diet might be considered to be an appropriate intervention for a person with dementia. These criteria were then adopted for use across all sites.

- Pretesting of the intake and 6-month follow-up instruments for length and ease of administration and understanding of questions was completed by the evaluation team prior to the introduction of these instruments into the field.

- Finally, during the demonstration implementation phase, sites called in on an as-need basis on the average of about once a week (across all sites) for information/consultation or simply discussion on a variety of topics related to their day-to-day work in the field. Often they wished to discuss or have clarified matters pertaining to expectations of the demonstration or HCFA policies as they related to the demonstration. Among issues discussed have been whether or not people with Multiple Sclerosis are appropriate for the demonstration, redefinitions of rollovers for certain cases, and determining responsibility for transporting clients when they enter or leave a health facility.

On occasion case managers needed advice on how to deal with a difficult situation, such as how to talk to a physician when the case manager is certain that alternate types of medication are needed (solution: have the consulting physician for the demonstration site talk with the physician directly), or how to handle a sticky situation where a caregiver thought she had fallen in love with her case manager (assign a new case manager of the same gender as the caregiver).

Often, case management staff simply requested assistance with a particularly difficult case. Some of the more interesting consultations have involved:

- The caregiver who simply left her husband who had Alzheimer's disease on the front porch of the demonstration project office, phoned her case manager to tell him the client was there, and checked herself into the hospital where her physician said she was not to be disturbed.

- The client who, although going to an Alzheimer's day care center, kept loaded guns in the house and for years physically abused his wife. This was a situation which had

continued for some time in spite of regular visits from a VA psychiatrist who apparently had not seen fit to either remedy or report the situation until our case manager became involved.

- The case where, when the case manager went out to do the assessment, she realized the "caregiver" was more severely psychiatrically impaired than the client and had to make arrangements to institutionalize the caregiver before the client's needs could be addressed.

- The case where two older sisters who are in their nineties were caregivers for their youngest sister who is totally bedridden and unable to recognize her surroundings. The two older sisters have learned to provide almost a skilled level of nursing care around the clock for their youngest sister and plan to continue to do so until she dies.

As is probably to be expected in this type of demonstration, the site staff uncovered many heart rending and poignant situations where caregivers and their care receivers are making heroic efforts to survive in the community against overwhelming odds. The efforts of the case managers to assist caregivers in these situations are often extremely creative and above and beyond the call of duty. They became experts at drawing on both informal and formal resources in order to support caregivers in these efforts. The case managers have informed us that the skills and abilities they have learned in order to do this have been acquired as a result of their work in the demonstration. If nothing else, the demonstration has helped them understand that it is possible to make the process of caring for someone with Alzheimer's disease a less stressful and more manageable experience for caregivers and patients alike.

Appendix Three

The Evaluation Design and Research Questions

STUDY DESIGN

An experimental study design was implemented to test the impact of the Medicare Alzheimer's Disease Demonstration. Six sources of data were used to measure the effects of the demonstration. The data sources included:

- Family application and physician forms for each applicant.
- Baseline intake interview for all treatment and control members and their primary caregivers.
- A 6, 12, 18 and 24-month follow-up interview with the caregivers of members of the treatment and control groups.
- Medicare claims data to obtain information on service utilization and expenditures for the treatment and control groups.
- Administrative reporting to HCFA covering demonstration costs, site activities, staffing changes, etc.
- In-person discussions during the site visits with key individuals affiliated with the demonstration in order to obtain qualitative and quantitative assessments of program operations, start-up and implementation issues, and lessons learned from the demonstration.

Baseline data collection began December 1, 1989, and clients were enrolled in the study through November 30, 1991. Each client was followed for up to 24 months with the final follow-up interviews being completed by November 1993. The evaluation instruments, key variables, and data collection procedures are summarized below.

DATA COLLECTION INSTRUMENTS AND PROCEDURES

Application and Intake Forms

The research design called for the intake interviewers at each site to play a key role in collecting baseline data for both clinical and research purposes. Specially trained and supervised by the evaluators, the intake interviewers were responsible for reviewing completed Family Application Forms and Physician Forms, conducting the baseline Intake Interview and submitting the applicant's name to the evaluators for randomization to the treatment or control group.

Family Application and Physician Forms

At each site the intake interviewer was responsible for obtaining the forms necessary to determine program eligibility. These forms included: the Family Application and Physician Form. The Family Application Form obtained information on the client's address, telephone number, social security number, Medicare number, Medicaid status and number, current living arrangements, client's demographic characteristics, client's informal caregivers, client's primary care physician, legal guardian, and responsible family members. The Physician Form requested data from the applicant's primary care physician on the patient's type of dementia diagnosis and other medical conditions. When the forms were received, the intake interviewer reviewed them for completeness and made a determination of program eligibility.

Baseline Intake Interview

If the applicant met the four demonstration eligibility criteria described earlier, a baseline interview was conducted by an intake interviewer with the applicant's primary informal caregiver or a formal paid provider if the applicant had no informal supports. An MMSE was also conducted with each client. The baseline Intake Interview gathered data in 21 domains:

- Client's demographic characteristics
- Client's beneficiary status
- Client's living arrangements
- Client's physical health
- Client's cognitive and functional impairment
- Client's mental status
- Client's unmet needs
- Client's informal supports
- Client's utilization of formal services
- Caregiver's demographic characteristics
- Caregiver's living arrangements
- Caregiver's employment
- Caregiver's physical health
- Caregiver provision of informal care
- Caregiver's assessment of client's dementia
- Caregiver's assessment of client's behavioral problems
- Caregiver effects of caregiving
- Caregiver's depression
- Caregiver's functional impairment
- Caregiver's use of support services.

As part of the intake process, the intake interviewers were responsible for providing applicants with a written packet of materials about the demonstration, the randomization process, and the use of data obtained from the study. A signed Informed Consent Form was also obtained during the initial in-home interview.

After the baseline Intake Interview was completed, the applicant's name was submitted to the evaluators for randomization. The original Intake Interview was sent to the evaluators for review and data processing. For applicants who were randomized into the treatment group, a copy of the Intake Interview was given to the demonstration site case management staff who incorporated much of the information into the baseline clinical assessment the case managers conducted to determine clients' service needs and develop care plans.

Random Assignment

The procedures for random assignment were straightforward. The intake interviewer filled out a Randomization Form specifying key identifying characteristics of each applicant from information available on the Family Application and Intake Forms. Then, at a predetermined time each week, one intake interviewer from each demonstration site contacted the evaluator and verbally transmitted the data required on the Randomization Forms to a member of the evaluation team. The evaluation team member simultaneously entered the data into a computerized randomization program that immediately assigned each applicant to either the treatment or control group. The randomization algorithm was designed to ensure that intake staff could not "game" the system and to ensure an overall balance between the number of cases assigned to treatment and control.

Follow-up Caregiver Interviews

The primary informal caregiver of each treatment and control group member was interviewed by telephone at 6, 12, 18, 24 and 36 month intervals after date of entry to the study. The evaluators hired and trained as research interviewers nurses and social workers in each of the local communities. Each interviewer was given an assigned caseload to follow throughout the study period. The follow-up caregiver interview covered each of the 21 domains included in the baseline interview as well as a series of questions to measure caregiver satisfaction with services received by the client.

Medicare Records

Medicare claims data was the source of information on the use and reimbursement of services covered by Medicare. Services normally covered under Medicare Part A include hospital stays for acute care and post-hospital extended care services, such as stays at skilled nursing facilities and service provided by home health agencies. Medicare Part B services include visits to physicians and ambulatory facilities, as well as physical and occupational therapy, speech pathology, laboratory and radiology services, and the purchase of durable medical equipment.

Administrative Reporting to HCFA

Sites were responsible for two main types of administrative reporting to HCFA. Each site prepares a monthly report highlighting site activities, staffing changes, and other relevant information. Each site also submits cost reports on administration, intake, case management and training costs. These reports are used by the evaluation team as a source of data for the process evaluation (discussed below).

Process Analysis

The goal of the process analysis is to provide an understanding of the manner in which the demonstration was actually implemented and of the processes and relationships through which it functions. The analysis in Chapter Three examines whether the demonstration and evaluation designs were carried out as planned and the lessons learned from running the demonstration and their implications for implementing similar programs in the future.

SAMPLE ATTRITION AT THE 6-MONTH FOLLOW-UP

Overall, sample attrition during the first six months of the study was slightly higher in Model B (11.2 percent) than Model A sites (8.9 percent). For both models the two primary reasons for attrition were death (5.5 percent in each model) and permanent institutionalization (2.6 percent in Model B and 1.3 percent in Model A). Less than 2 percent of clients attrited for other reasons (e.g., moved out of catchment area, lost to follow-up, refusal).

In the Model B sites, there was slightly more attrition in the control group (11.7 percent) than in the treatment group (10.8 percent) primarily due to higher proportions of control clients who died. In the Model A sites there was almost no difference in client attrition at six months (treatment group 9.0 percent, control group 8.8 percent). In both models, a slightly larger proportion of the treatment group members became permanently institutionalized during the first six months of the study, while a slightly larger proportion of the control group died.

DEMONSTRATION EFFECTS

The two intervention models were expected to have similar impacts on clients and caregivers compared to the control group, but the magnitude of the impacts of the two models were expected to vary given differences in case management intensity and in the monthly reimbursement caps that are allowable per client. Because of its 1:100 case manager to client ratio and its lower allowable monthly service expenditure cap, we expected that clients and caregivers served under Model A would exhibit less dramatic changes in a variety of outcome measures than those served under Model B with its 1:30 case manager to client ratio and higher monthly expenditure caps.

Because the majority of care for community resident persons with Alzheimer's disease and related disorders is provided by informal (i.e., unpaid) sources (Rice et al., 1993), usually a spouse or adult female child, the demonstration interventions were designed to provide limited formal service support to caregivers under the assumption that such support be beneficial for informal caregivers and help them sustain their caregiving role over time. Assistance for the caregiver in both accessing (case management) and paying (monthly reimbursement allocation) for home and community-based services was envisioned as affecting a number of outcomes that are hypothetically related to caregivers' ability to maintain their roles as the primary providers of assistance to people with dementia.

Outcomes hypothesized to affect caregivers' ability to maintain their caregiving role will be discussed in detail below and include self-assessment of health, stress and burden, depressive symptoms, social activity limitations, unmet need for assistance in caring for the demented person, life satisfaction, and informal support network characteristics. Also included are the characteristics of the person for whom they provide care. These include ADL/IADL impairments, cognitive impairment, living arrangement, behavior problems, and level of supervision required. The specific research questions and their related hypotheses relevant to the examination of the impacts of the demonstration interventions on clients and caregivers are examined below.[1]

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[1] An issue that was originally included in the MPR design work was whether community outreach efforts mandated by the demonstration assisted in the identification of previously unidentified persons with Alzheimer's disease and related disorders. Although it was originally envisioned that the demonstration would provide diagnostic work-ups for clients who may require one, the costs associated with this procedure was deemed to be too high given the monthly reimbursement caps. Although sites were free to pay for diagnostic work-ups, none were provided as a demonstration service. Since we relied on the applicant's physician to attest to the fact that a client had an irreversible dementia, we could not assess whether the demonstration assisted in the identification of previously unidentified demented persons.

RESEARCH QUESTIONS

Each research question and the rationale for the assumed effects of the demonstration interventions will be discussed in detail below.

Impacts on Persons with Alzheimer's Disease

Research Question 1: In what ways do services provided under the Demonstration affect the placement of clients in institutional care settings over time?

In the demonstration, case management and the assessment of client needs may have assisted in identifying and treating medically-related problems earlier for the treatment group. The availability of demonstration in-home and community-based supportive services would result in a reduction in use of high-cost service alternatives (e.g., in-patient and nursing home care) and an increase in the use of less costly services (e.g., outpatient physician). Nursing home days would be lower for the treatment group due to the availability of demonstration in-home and community-based services which will allow demonstration caregivers to continue to care for clients for longer periods of time than caregivers in the control group. Due to the progressive, irreversible character of dementing illnesses, there will be no difference in mortality rates between the treatment and control groups.

Impacts of Client Service Use and Costs

Research Question 2: In what ways do the Demonstration interventions affect home and community-based service utilization and service satisfaction over time?

It was expected that the mix of services utilized by treatment group participants would be broader due to the increased access to a wider variety of services and increased affordability of services resulting from the treatment group benefit from Medicare. The demonstration benefit would combine to enhance resources already being utilized by treatment group participants and would reduce economic barriers to service use.

Service providers for five services (social day care, personal care services, homemaker/chore services, companion services) provided to demonstration clients received special training on how to work with demented clients. In addition, all demonstration case managers received special training on working with demented clients and their families. It was anticipated that this special training would have a positive impact on treatment group caregivers' level of satisfaction and assessment of quality of services they received under the demonstration compared to control group clients who received these services from providers who did not receive special training.

The use of formal services is often thought to aid in reducing caregiver stress and burden by providing, at a minimum, respite from the duties of caregiving. As noted earlier, based on the research conducted so far, caregivers consistently underutilize the formal services available to them, even when they are provided at low cost (cf., Biegel, Bass, Schulz, & Morycz, 1993; Caserta, Lund, Wright & Redburn, 1987; Bass & Noelker, 1987; George, 1987; U. S. Congress Office of Technology Assessment, 1990; Swan & Estes, 1990; Parris-Stephens, 1993). This underutilization is not distributed evenly across all categories of caregivers. Research on the use of services by caregivers has shown that it is the most socially isolated caregivers providing the most intensive levels of care who are not participating in the formal service system (George, 1986; Parris-Stephens, 1993). While need for a service appears to be the major predisposing factor in service utilization, a number of reasons for nonuse have been identified, including lack of knowledge of service availability, lack of knowledge about how to arrange for services, the cost of services, the fear of future illness-related costs that made caregivers reluctant to spend money in the present, concern that others would view the caregiver negatively if they obtained caregiving help,

embarrassment at the care recipient's behavior, or the fear of upsetting the care recipient (cf., Mullen, 1993; Swan & Estes; 1993; U. S. Congress Office of Technology Assessment, 1990). In addition, some caregivers indicate that they don't need services, either because they do not feel burdened or because they do not regard their relative with dementia as having a disease (Parris-Stephens, 1993). Since the demonstration interventions hypothetically would address some of these utilization barriers, the reasons for non-use of services were expected to be fewer in the treatment group when compared with the control group.

Research Question 3: In what ways do the Demonstration interventions affect traditional Medicare service costs over time?

It was expected that there would be lower inpatient and outpatient Medicare costs for the treatment group due to contact with case managers and other formal service providers reimbursed by Medicare. This contact would result in early identification of health problems where they could be prevented and/or treated on an outpatient basis and before they required inpatient hospitalization or institutionalization. Although combined client inpatient and outpatient services may have been lower for the treatment group, any differences would be negated by the additional costs of the expanded long term care benefit available to the treatment group resulting in higher overall expenditures for the Medicare program after including home and community-based expenditures.

Impacts on Caregivers

Research Question 1: In what ways do services provided under the Demonstration affect caregiver health over time?

A number of studies have shown that caregivers of functionally impaired elderly people are more likely to report health problems than caregivers of functionally intact elders (Silliman & Sternberg, 1988; Horowitz, 1985). It was expected that through contact with demonstration case managers and other health providers, caregiver health problems would be identified when they could be prevented or treated on an outpatient basis and before they required hospitalization resulting in lower caregiver outpatient visits and lower caregiver inpatient visits. Functional abilities of treatment group caregivers were expected to decline more slowly than the control group as a result of higher demonstration service utilization. These interventions would attenuate the adverse health affects of caregiving.

Research Question 2: In what ways do services provided under the Demonstration affect caregiver support networks over time?

With the additional in-home services available from the demonstration. It was expected that there would be a shift in the types of services the primary caregiver provided, but no decline in primary caregiving hours. Other studies have found that in-home and day care services help reduce caregiver stress and burden, but do not result in decreased levels of caregiving by the primary caregiver.

As part of the case management intervention, case managers assessed the caregiving situation of each client by identifying the primary caregiver and the extent of other family members' and friends' involvement in caregiving. In situations where the primary caregiver was extremely frail or burdened with caregiving, case managers assisted in getting other family members involved.

The frequency and intensity of patient memory and behavior problems have been associated with increased caregiver burden as well as with the caregiver's decision to institutionalize the patient (cf., Cohen, et al., 1993; Hamel et al., 1990). Social support is thought to buffer or mediate an individual's response to stressful situations (cf., Pearlin et al., 1990) and has been associated with effective coping styles (cf., Parks & Pilisuk, 1991) and with lower levels of depression (Fiore,

Becker, & Coppel, 1983). The use of formal services is also thought to aid in reducing caregiver stress and burden by providing, at a minimum, respite from the duties of caregiving. Despite the generally high levels of distress among caregivers to Alzheimer's patients, their rate of formal service use is lower than that for caregivers of older adults with other illness conditions (U. S. Congress Office of Technology Assessment, 1990). This under utilization of services by caregivers potentially can lead to caregiving "overload" and the caregiver's giving up the caregiving role; either to other family members or to formal providers (e.g., placement in supportive housing or in an institution). The case management intervention, along with support services provided by specially trained service providers in the demonstration was expected to reduce caregiver stress and burden and alleviate caregiver "overload".

Research Question 3: <u>In what ways do client and caregiver services provided under the Demonstration affect caregiver well-being over time?</u>

Frequency and intensity of patient memory and behavior problems is associated with increased caregiver stress and burden as well as with a caregiver's decision to institutionalize the patient (cf., Cohen, et al., 1993; Hamel et al., 1990). There is mounting evidence that providing care to a family member with Alzheimer's disease can also lead to various psychiatric symptoms (cf., George & Gwyther, 1986; Schulz, Visintainer, & Williamson, 1990). In addition, caregivers may experience greater limitations in employment opportunities and/or exiting the work force due to the client's dementia care needs (e.g., the behavior problems that can accompany memory loss) that require greater caregiver supervision, assistance, or attention resulting in lower life satisfaction. Behavior problems exhibited by demented persons often limits both the willingness of caregivers to accept services and the willingness of service providers to deliver services.

Due to the case management intervention, caregivers received specialized education and training about the disease, information about available services, and access to services through the expanded Medicare benefit. Due to these interventions, treatment group caregivers were expected to be afforded a much needed respite from caregiving, reducing isolation and loneliness, provided an opportunity to share feelings and experiences in a supportive environment with peers who share similar concerns, provided caregivers with support, understanding, affirmation, and validation of thoughts and feelings about caregiving, normalizing caregiver's experiences, instill hope, educate caregivers about Alzheimer's disease and inform them about community services, and to aid in developing problem solving abilities.

Concerns of caregivers regarding the receipt of formal services were expected to be effectively addressed by the treatment intervention (contracts with quality providers, specialized dementia training of service providers by demonstration staff, etc.). As a result, unmet service needs would be reduced for the treatment group participants and they would have lower stress and burden and depression scores, fewer employment and/or social limitations, fewer unmet ADL/IADL needs, fewer perceived needs, and greater satisfaction with client services, and greater life satisfaction.

Appendix Four

Description of the Demonstration Sites

The congressional mandate for the demonstration specified that the evaluator provide a description of the demonstration sites and the project's implementation process. Sites visits were conducted at each of the eight sites during the months of June and July 1990. This time frame was selected so the sites would have enough time to "iron out the wrinkles" associated with the beginning of a major demonstration project, but early enough so that implementation issues could be adequately documented.

A mixed methodology was employed combining a semi-structured questionnaire and the use of probing questions during the site visit discussions. The questionnaire was mailed to site directors prior to the site visit so staff would have an opportunity to prepare responses to the questions. The questionnaire contained questions regarding: 1) the history and sponsorship of the demonstration; 2) the interorganizational structure of community agencies leading the local demonstration implementation effort; 3) the local service environment of the demonstration site; 4) client outreach and enrollment activities; 5) case management services; and 6) demonstration service utilization patterns. Questionnaires were developed for project directors, Alzheimer's Association representatives, service providers, local long-term care system experts, case managers/case aides, case management supervisors, host agency directors, and outreach-intake workers.

Additional data used for the site descriptions were derived from information reported on a monthly basis by each site through monthly site reports. These reports provided site-specific information on: 1) tracking of client applications; 2) tracking of active clients; 3) tracking of case management activity; and 4) accomplishments or difficulties encountered during the month.

Summary descriptions generated from these data are reported below by model and site. More detailed inmformation on site characteristics can be found in Newcomer et al.(1993). At the end of the chapter a brief summary of key program characteristics for each site is presented by model to facilitate cross-site comparisons. Model A sites are summarized in Figure 4-1, and Model B sites are summarized in Figure 4-2.

Model A Sites

Urbana, Illinois - Carle Clinic Association

The Medicare Alzheimer's Disease Demonstration in Illinois was sponsored by the Carle Clinic of Urbana-Champaign Illinois. Carle Clinic was started by two physicians in 1931 and was based on the model of the Mayo Clinic where the two doctors trained. In 1946 the organization split into two parts; one is a private, for-profit physician group corporation called the Carle Clinic Association. The other is a non-profit holding company called the Carle Foundation. Carle Clinic Association and the Carle Foundation (either together or singularly) owned and operated a full range of vertically integrated health care services.

The Carle Clinic and Carle Foundation were interested in expanding their programs to the growing elderly population in East-Central Illinois and felt they could build on their experience with the Kellogg case management program to provide the coordination and services needed by the Alzheimer's population. Support for the project was sought and obtained from the East-Central Illinois Area Agency on Aging, the University of Illinois-Champaign- Urbana, and the other major medical provider in the Bloomington-Normal area, Bromen Healthcare.

The Medicare Alzheimer's Disease Demonstration operated out of six service centers in four locations in East-Central Illinois, including the administrative central office in Champaign, Illinois and site locations in Danville, Decatur, and Peoria. The demonstration covered the following 20 counties in Central Illinois: Champaign, Christian, Coles, Dewitt, Douglas, Edgar, Ford,

Iroquois, Livingston, Logan, Macon, McLean, Moultrie, Peoria, Platt, Sangamon, Shelby, Tazewell, Vermillion, and Woodford.

The 20 counties served by the Illinois Medicare Alzheimer's Disease Demonstration program covered an area of 13,364 square miles and accounted for over 237,880 persons 60 or older. The largest elderly concentrations in the 20 county area included Sangamon and Peoria counties, each accounting for 14 percent of the area's total population 60 or older; Macon county with 10 percent of the area's total population 60 or older; Champaign and Tazewell counties each accounting for 9 percent of the area's total population 60 and older; McLean and Vermilion counties each accounting for 8 percent of the area's total population 60 or older; and Coles County with 7 percent of the total population 60 or older. The rest of the counties' over-60 populations ranged from a high of 6 percent to a low of 1 percent. Over 10 percent of the area's total over-60 population lived in poverty while 28 percent were living alone. Thirty-five percent of the 20-county area's population was 75 or older. Fifty-six percent of the residents of the original 16 counties lived in rural areas.

Almost 4 percent of the area's total population were minorities including 3.2 percent Black, .09 percent American Indian, .23 percent Asian, .9 percent Hispanic, and .01 percent Other minority. Sixty-six percent of the total minority population in the original 16 counties lived in poverty. Over 5 percent of the area's total over-60 population resided in nursing homes and there were almost 10,000 licensed nursing home beds within the original 16 county catchment area.

Demonstration service centers were located in Champaign-Urbana and serve Champaign, Coles, Douglas, and Ford counties; in Bloomington and serve Livingston, McLean, Peoria, Tazewell and Woodford counties; in Danville and serve Edgar and Vermilion counties; and in Decatur and serve Christian, DeWitt, Macon, Piatt, Sangamon, Shelby, and Moultrie counties.

Under the assumption that 4 percent of the elderly would be cognitively impaired as a result of Alzheimer's or related dementias, it was estimated that approximately 5,352 elderly would be eligible for the demonstration. The Illinois demonstration's initial project census was 400 (200 treatment clients and 200 control clients).

In July 1990, the original census goals were raised by 200 cases (100 treatment and

100 control) to a total of 600 active treatment and control clients. In May 1991, enrollment projections were increased again, from 600 to 800 active clients. By April 30, 1991, the Illinois site had enrolled a total of 728 clients, of which 22 percent (or 163 clients) attrited from the sample due to death, institutionalization, or moved out of catchment area. The final sample census was 565 clients (284 treatment and 281 control) as of April 30, 1991. Overall, the Illinois site was successful in reaching its enrollment goals, averaging 53 applications per month during the 17-month enrollment period of the demonstration.

The Community Long Term Care Service System

The 20 counties covered by the demonstration were predominately rural with four major urban centers, Bloomington-Normal, Decatur, Peoria and Urbana-Champaign. Rural communities are facing serious challenges in serving the elderly with a growing need for health, long-term community care, and transportation services. Specifically, rural areas are said to need respite care for families providing constant care for older persons. There is also a shortage of qualified home care workers due to low job prestige and inadequate wages, benefits, and travel allowances. Transportation is a major concern for most older people and the East-Central part of Illinois is said to be in need of more funds and vehicles to provide door-to-door, demand-response services to link seniors in rural areas to health care, social services, senior dining programs, and senior centers.

East-Central Illinois is served primarily by the East-Central Illinois Area Agency on Aging, Inc. which plans, coordinates, and advocates for the development of a full range of services to promote the health, independence, and dignity of older persons and helps families carry out their roles as caregivers in East-Central Illinois. These services included access services such as case management, information and referral, outreach, transportation and escort services; community-based long-term care services such as home delivered meals, home health, homemaker, chore/housekeeping, home repair, in-home respite care, and adult day care; community-based services such as congregate meals, legal assistance, counseling, and multi-purpose senior centers; and services to seniors in long-term care facilities such as a sub-state Ombudsman program and coordination with other community-based services for seniors.

Services were somewhat limited and accessibility uneven in the Illinois Medicare Alzheimer's Disease Demonstration catchment area. The only case management program available in the East-Central Illinois catchment area was through the Illinois Department of Aging Case Coordination Units (CCU). This program provided an initial evaluation visit to the family that is available to everyone. In order to receive funded services and ongoing case management, individuals must have met asset guidelines, as well as functional assessment standards. There were a limited number of case managers and some serve more than one county. There was one geriatric assessment clinic and one Memory Disorder Clinic in the catchment area. There was one designated information and referral agency in each of the 20 counties. Hospitals, mental health centers, and social service agencies throughout the region also provided information and referrals. There was at least one Medicare certified home care agency in each of the 20 counties. There were a very limited number of occupational therapists, physical therapists, and speech therapists available.

Homemaker/personal care services were available throughout the 20-county area but there was a consistently low number of workers attracted to this work. Part of this staffing retention problem stemed from poor wages. There were meal programs available throughout much of the area, but there was a problem with delivery in the rural areas and very limited ability to provide special meals. Adult Protective Services and mental health counseling for the elderly population were limited. Transportation was available in most larger communities but availability in the rural areas was minimal and not able to adapt to individual schedules.

Hospice and adult day care services were limited. There were ten half-day adult day care programs that serve portions of ten of the twenty counties. This left ten counties without adult day care services. Respite care, training for informal caregivers, and support services for informal caregivers were minimally available. Finally, there was an inadequate number of senior citizens housing facilities. At this point, there was no congregate or foster care housing, only a few board and care homes, and a few continuing care retirement communities. The latter served those with higher incomes. ICFs were available, but in many areas these functioned with a waiting list. Both ICFs and SNFs had staff retention problems apparently due to low wages.

Consistent with the lack of services within the Illinois Medicare Alzheimer's Disease Demonstration catchment area, there were access problems for dementia patients. The usual entry points for dementia patients to the community-based care system included physicians, hospital discharge planners/social service staff, and CCUs. Among the reported barriers to services for dementia patients were service providers' reluctance to serve combative or aggressive patients, the inability of home care workers to cope with dementia patients (e.g., they have no special training in dementia), the high cost of private duty respite care, and denial of the disease by dementia patients and their caregivers.

There was a need for more nursing homes which specialized in the care of dementia patients since many facilities in East-Central Illinois were not equipped to provide

24 hour monitoring of dementia patients who wander. Due to concerns about liability, some nursing homes have attempted to discharge dementia patients alleging that they are a "harm to themselves and others." It was the opinion of some long term care experts in the East-Central Illinois catchment area that the current practice of "mixing" dementia patients with other residents in nursing homes created a disruptive atmosphere, denied the dementia patients proper care and treatment, and robbed the other residents of their privacy. Furthermore, some dementia patients do not need intermediate or skilled nursing home care but were placed in nursing homes because the family refuses or is unable to provide care at home. The unnecessary placement of dementia patients in ICF and SNF facilities reduced the availability of nursing home care to other patients. Finally, more specialized housing and treatment facilities were said to be needed for dementia patients.

Alzheimer's patients had access to some specialized services within the Carle Clinic organization. The medical practice had a geriatrician and a neurologist on staff to provide consultations, and the Carle nursing home had two dementia units as well as the adult day care center. There were also a few drug studies going on in the Champaign-Urbana site which focused on Alzheimer's patients.

The Community Care Program (Medicaid waiver program) competed with the Alzheimer's demonstration for clientele. The Community Care program required an income of under $10,000, and has other asset limitations. There were annual income and functional status re-evaluations. The Community Care program benefits included day care, homemaker/chore, and case management. There is no waiting list of services once eligible. The program was offered in all of the demonstration locations. The strength of the program varied, depending on the local implementation contracts. A limited number of persons in the Community Care program were accepted into the demonstration treatment or control groups according to the randomization protocol.

Demonstration Service Providers

The host agency in the Illinois Medicare Alzheimer's Disease Demonstration was the sole provider of demonstration case management services. Originally, as the program attempted to establish service contracts with outside community-based service providers, they found that many providers were wary of the "Carle Organization" coming into their counties. This was seen as an attempt to "take over their territory." Accordingly, several providers were reluctant to enter into contracts with the program or to refer potential clients. This was especially true when developing referral contacts with non-clinic physicians. In time, the MAP staff were able to develop good networking and working relationships with most providers in its catchment areas. In the end, the program developed a number of provider contracts in each of its six service areas.

The primary reasons for subcontracting were: the host agency did not offer the service; the client already had an ongoing relationship with another provider; and/or the client lived in an area where the service was geographically more accessible through another provider. Case managers were given a great deal of freedom in determining the appropriate service provider for each client. The project director and project manager were responsible for negotiating the contracts needed within the catchment area. Generally, the demonstration project matched each service provider's prevailing rate.

Carle Clinic provided Medicare certified home care services for the Danville and Champaign sites while Carle Medical Supplies provided medical supplies and equipment from its Champaign location to all five MAP locations (Champaign, Bloomington, Danville, Decatur, and Peoria). The Peoria site contracted with the same service providers as the Bloomington/Normal site. Carle Foundation provided adult day care for the Champaign-Urbana center. The remainder of the services were subcontracted. The Illinois Medicare Alzheimer's Disease Demonstration

subcontracted with a total of 77 service providers, some serving clients in more than one county, in the 20-county catchment area. Subcontracted services included:

Bloomington/Normal/Peoria catchment area: 21 service providers

- Medicare certified home health care
- home delivered meals
- adult day care
- homemaker/housekeeper/chore services
- medical supplies, adaptive & assistive equipment
- durable medical equipment, consumable care goods
- companion services
- counseling
- transportation
- outreach

Danville catchment area: 15 service providers

- medical supplies, adaptive/assistive equipment, durable medical equipment, consumable care goods
- transportation
- homemaker/housekeeper
- home delivered meals
- chore services
- adult day care
- certified home care services
- family counseling, mental health services

Decatur catchment area: 22 service providers

- medical supplies, adaptive/assistive equipment, durable medical equipment, consumable care goods
- transportation, outreach
- homemaker/housekeeper/chore services
- companion services
- home delivered meals
- Medicare certified home care
- adult day care

Champaign-Urbana catchment area: 19 service providers

- adult day care
- Medicare certified home care
- medical supplies, adaptive/assistive equipment, durable medical equipment
- family counseling, mental health services
- homemaker/housekeeper/chore services
- transportation services

Compliance with the Case Management Model

The Case Management Model was one of the primary interventions tested under the demonstration. To help ensure that each site maintained the appropriate case manager-to-client ratio during the caseload build-up phase of the demonstration, the sites were required to provide monthly reports on the amount of time each case manager was spending on case management related activities and the number of active cases for each case manager. With this information, it was possible to monitor the case manager-to-client ratio to determine if the project was complying with the Model A criteria of one case manager per 100 clients. The sites were allowed a 5 percent variance above or below the client-to-case manger ratio during the caseload build-up phase due to addition of clients, transitions in cases, addition of staff, etc. For the Model A sites, this variance could range from 95 and 105 active cases per case manager and not be out of compliance with the Model A criteria (e.g., new cases coming on; clients terminated due to death or institutionalization).

The Illinois sites' case manager-to-client ratios ranged from a low of 1 case manager to 34 clients in February 1990 to highs of 1 case manger to 106 clients in December 1990 and May 1991 and one case manager to 111 clients in June 1991. The site was not truly in compliance with the case manager-to-client model until December 1990 and even then, the ratios fluctuated above as well as below the 1 to 100 model into April/June of 1991. The case managers in the Illinois sites were spending more than the 1 to 1 1/2 hours per client as required in the Model A ratio.

Rochester, New York - Monroe County Long Term Care Program, Inc.

Three agencies sponsored the Medicare Alzheimer's Disease Demonstration in Rochester, New York: the Monroe County Long Term Care Program (ACCESS), the Visiting Nurse Service of Rochester (VNS), and the Monroe County Health Department (MCHD). ACCESS is the primary agency. The proposal was reviewed and supported by the ADRDA, Rochester.

ACCESS, the VNS, and MCHD had previously implemented two major HCFA demonstrations of coordinated community-based care as well as a randomized case management study funded by the Robert Wood Johnson Foundation. From 1977 to 1986, Medicaid and/or Medicare waivers allowed the three organizations to provide community-based programs for long term care patients in Monroe County. The previous demonstrations/studies conducted in Monroe County included a number of patients with Alzheimer's disease and related disorders and the clients remain a significant portion of the caseloads of the three agencies today. Many staff participating in the MAP demonstration were with ACCESS during the previous Medicare demonstrations, including the Executive Director of the program.

The ACCESS program was established in 1975 as the community-based program designed to coordinate and develop alternatives and administer funds for long term care for the elderly and adult disabled in Monroe County, New York. Services provided since its inception include information and referral as well as case management. Over the years, ACCESS has developed a number of long term care programs, including a Medicaid Section 1115 waiver program (1977-1985), the first HCFA demonstration program to implement comprehensive assessment as part of case management for long term care patients; a Medicare Section 222 waiver demonstration program, ACCESS: Medicare (1982-1986), which financed comprehensive assessments and case management for Medicare patients at risk of institutionalization and provided 100 days of home care and 100 days of nursing home care annually; a team model of case management funded by the Robert Wood Johnson Foundation (1983-1985); and ACCESS: Select, a self-pay information and referral, assessment, and service coordination/monitoring service. ACCESS: Select is a member of Work/Family Elder Directions' nationwide network of counseling and referral agencies created to serve corporate employees and retirees and their families.

The central feature of ACCESS has been its case management program for long term care patients living at home. The average daily census of the Medicaid case load managed by ACCESS has increased from 182 in 1978 to 900 in 1989. The self pay program has served more than 700 clients and their families since 1985 while the ACCESS:Medicare program served 2,200 clients from 1982 to 1986. In the past ten years, over 2,000 individuals with Alzheimer's disease or related disorders have been case managed by ACCESS.

Since its inception, ACCESS has been working with VNS and the MCHD to improve the effectiveness of the long term care system in Monroe County, New York. Two earlier joint efforts between ACCESS, VNS, and MCHD were carried out through the ACCESS:Medicaid Section 1115 and Medicare Section 222 demonstrations. The VNS and MCHD provided the clinical case coordination and many of the direct services these clients required. The purpose of the Robert Wood Johnson Foundation case management study was to test a new approach for managing the care of seriously chronically ill elderly living in the community.

The Visiting Nurse Service of Rochester and the Monroe County Health Department Home Health Agency are certified home health agencies. Both organizations offer a wide range of home care services to the elderly, disabled, and terminally ill. The VNS of Rochester, the first home health care agency in Rochester, was founded in 1919. VNS provided the following in-home services: skilled nursing, home health aide, homemaker/personal care aide, meals/food service, durable medical equipment, and consumable care goods. Today, VNS serves an active patient caseload of approximately 1,800 people at any given time.

The Monroe County Health Department was organized in 1958. Its home health agency differs from VNS in that it has a major health promotion and disease prevention focus. It is mandated to provided maternal and child health care, immunizations, and mental health services. The MCHD home health agency provides skilled nursing at home. The MCHD home health agency had 140 employees and an active caseload of 1,500 patients, excluding maternal and child health clients. Both the VNS and MCHD provided services 24 hours a day, 7 days a week and had a hotline system for evenings, nights, holidays, and weekends. Each agency had a supervisor and nurses available to make visits after hours to handle patient care problems.

As a result of its history with three case management model demonstrations, ACCESS decided to apply for the Medicare Alzheimer's Disease Demonstration award. ACCESS developed the proposal, in conjunction with VNS and MCHD as subcontractors to ACCESS, with ACCESS as the lead agency in much the same way they had worked together on past demonstration projects.

The Medicare Alzheimer's Disease Demonstration operated out of one agency in Rochester, New York and served all of Monroe County, New York. Early in the demonstration build-up phase, the program expanded into four adjacent rural counties including Ontario, Wayne, Livingstone, and Yates counties. ACCESS was responsible for all administrative, case management, outreach and intake, and fiscal activities and housed all of the program's administrative, supervisory, case management, outreach and intake, fiscal, and support personnel.

The catchment area served by ACCESS included Monroe County, situated on the north-central part of upstate New York. Monroe County includes the city of Rochester as well as suburban and rural areas. The population of Monroe County was about 725,000, of whom approximately 80,000 are noninstitutionalized elderly. Assuming that 4 percent of the noninstitutionalized elderly had Alzheimer's disease or related dementia, approximately 3,200 demented Monroe County residents living at home were eligible for the demonstration. The site assumed that 50 percent of those 3,200 elderly residents would be referred to the demonstration and that 50 percent of the 1,600 referred applicants would agree to participate. Furthermore, the site assumed a 15 percent drop-out rate, leaving 680 persons eligible to participate in the demonstration.

The population of Monroe county in 1980 was predominantly White and relatively wealthy with a median household income of over $20,000 and a per capita income of over $8,000 annually. Eighty-eight percent of the population lived within an urban catchment area. Eighty percent of the population of Monroe County were White, 10 percent were Black, 2 percent were Hispanic, and 8 percent were Other. Almost 9 percent of Monroe County resident lived below the poverty level in 1980.

In 1980, the aged made up 11 percent of the population. By 1985, the elderly population had increased to 85,157 residents, or 11.9 percent of the population with 5 percent of the elderly 75 or older and approximately 1 percent over the age of 85. The majority of those over age 65 are White (97 percent) and female (62 percent). Three-quarters of the elderly had incomes below $10,000 and 7.4 percent of the elderly were below the federal definition of the poverty level.

ACCESS originally proposed to enroll 540 participants (270 in the treatment and 270 in the control group). However, after the award, the ACCESS program increased its numbers to 300 treatment and 300 control participants. Later in the client enrollment buildup phase (April 1991), the ACCESS MAP raised the census goals for the program to 800 cases (400 treatment and 400 control). A total of 670 clients had applied to the program by April 1991; 134 clients, or 20 percent of total client applicants, had attrited due to institutionalization or death or had moved out of the demonstration's catchment area by April 30, 1991. On April 30, 1991, the New York demonstration site had 536 clients enrolled; 263 treatment clients and 273 control clients.

The Community Long Term Care Service System

The state of New York is unique in that most in-home service agencies must be licensed by the state and services in the home must be ordered by a physician. In addition, each licensed agency must conduct its own assessment on a client before providing services, even if a case manager from another agency has already conducted a client assessment. In Monroe County, the MCHD provided the physician mandated home health services along with the Department of Senior Services. All personal care, home health, and all health related services in the home, other than companion services, had to be performed by specifically trained and certified personnel. This was true for all services that came under the state's licensure law. As a result, ACCESS was required by the state health department to become licensed as a home health agency when they were awarded the Medicare Alzheimer's demonstration. Services that did not come under this state licensure law include support groups, companion services, and home repair, etc. Case managers in the demonstration had to have a physician sign off on their case plans. In addition, New York required a nurse assessment prior to services being provided in the home. This is why ACCESS' contracted assessment functions with VNS and MCHD. Thus, New York has a highly regulated service delivery environment.

The long term care service delivery system within the county was characterized by a wide variety of social and health service delivery providers. Access to services by dementia patients and/or caregivers was not restricted in Monroe County. There were two dementia diagnosis clinics in the county; one, the Alzheimer's Disease and Memory Disorders Clinic, housed at Strong Memorial Hospital, which was jointly sponsored by the University of Rochester Medical Center and Strong Memorial Hospital. The other diagnostic center was the Williams Geriatric Assessment Clinic at Monroe Community Hospital.

Other Alzheimer's specific services included an Alzheimer's Disease Assistance Center, funded by the state, which provided case management and support group services and the Alzheimer's Family Outreach Center, a Monroe Community Health Department program providing fee-for-service case management, multi-disciplinary assessment, and counseling services through Monroe Community Hospital. Rochester Rehabilitation Center also provided services to dementia patients through a

program called Project Reach, which assessed homebound chronically ill elderly (many of whom have dementia) and provided psychiatric home visits, care plan development, and counseling services; and the Monroe County Mental Health Department also provided services (e.g., case management) to dementia patients.

In addition, there was a 20 to 30 percent penetration by HMOs in the Rochester area (specifically, a Blue Cross-Blue Shield plan) that offered information and referral services to its members. The state of New York also had a program for dementia patients in a local nursing home with a dementia unit. There were Alzheimer's-specific respite programs and many home health aides and respite staff had Alzheimer's specific training. Finally, there was the Wilson Special Alzheimer's Program at the Jewish Home, which was a medical and social day health program. Other case management systems in Monroe County included four programs based on the nursing home-without-walls program. About 800 of 1,000 case managed clients from the Department of Social Services were transferred to these community-based case management programs. A total of four nursing home-without-walls programs were instituted in Monroe County. The state Medicaid program and a special New York state funded program also provided case management. The state funded program was for individuals who were above Medicaid eligibility limits but below 200 percent of the poverty level. It provided case management and home care services on a sliding fee scale.

Major access points for Alzheimer's patients to the service system came from primary care physicians, hospitals (e.g., hospital discharge planning units), home health agencies, nursing homes, and from families themselves. Barriers to access included families' and physicians' lack of knowledge of the services. A second major barrier was the cost of many of the services. Another complicating factor was the amount of time it took to become Medicaid certified in New York. While the Medicaid program is very generous (e.g., a Medicaid certified individual can qualify for 24-hour, 7-day-a-week home care through the program), many families did not want to spend down to qualify or they had too many assets to qualify.

Demonstration Service Providers

The ACCESS MAP project contracted with 53 agencies to provide services in the Monroe County area. VNS and MCHD were the primary "preferred provider" agencies, but contracts were negotiated with 53 other service agencies in the Rochester area. In addition, the local chapter of the Alzheimer's Association was given a contract to provide on-going training for the ACCESS staff on Alzheimer's disease, working with Alzheimer's patients and their families, and provide other dementia specific training. Case managers were given a great deal of freedom in determining the appropriate service provider for each client. Generally, the demonstration project matched each service provider's prevailing rate. Even with a service rich area like Monroe County, there were some problems with obtaining needed services for clients. Overall, the biggest problem for the agency was scheduling personal care aid. Since the usual service allotment was for two hours, it was difficult to find aides willing to work just two hours for a client. ACCESS attempted to deal with this problem by scheduling an aide for four hours on one day rather than two hours a day for two days. It was unclear how well that was working. However, there were few other problems that occurred with the contract agencies.

Services provided by ACCESS included:

- adaptive equipment - cognitive/physical
- chore services - general/repairs & maintenance
- companion services (including companion training)
- consumable care goods

- adult day care
- family counseling
- home health aide
- housekeeping
- medical assessment
- mental health service counseling
- medical supplies
- personal care aides
- transportation - client/caregiver
- skilled nursing

Compliance with the Case Management Model

During the client build-up phase the New York site fluctuated radically from a low of 1 case manager to 24 clients in February 1990 to a high of 1 case manager to 144 clients in March 1991. Overall, the New York site did not reach compliance with the Model A criteria until December 1990 and fell under the allowable low end to 1:85 in May 1991. The case managers in New York were spending slightly more than the allotted 1 to 1 1/2 hours per month per client by the end of the caseload build-up phase.

Portland, Oregon - Good Samaritan Hospital and Medical Center

The Medicare Alzheimer's Disease Demonstration Project in Portland, Oregon was sponsored by Good Samaritan Hospital and Medical Center (GSH&MC), a major medical center in the Pacific northwest. GSH&MC was part of Legacy Health Systems, which operated five hospitals and a home health agency in the greater Portland area. GSH&MC had extensive experience with community-based long term care having made a commitment in the late 1980's to offer a full spectrum of health and support services to chronically ill and frail patients and their families through its Departments of Neurology and Medicine. GSH&MC organized and developed in-home care, respite care, hospice, family support services, assessment clinics, and continuing care services. Its Alzheimer's Assessment Clinic provided an interdisciplinary evaluation including an in-home assessment, examinations by a neurologist or an internist as well as a psychologist, and laboratory testing followed by a family conference. GSH&MC also operated two long-term care facilities, one with a special Alzheimer's unit.

GSH&MC was also a participating institution in the Alzheimer's Disease Center of Oregon (ADCO). ADCO is a regional Alzheimer's "center without walls" and included the Portland Veterans Administration Medical Center, Oregon Health Sciences University, and state chapters of the Alzheimer's Association. During the first year of the demonstration project, GSH&MC in conjunction with Oregon Health Sciences University and the Portland Veterans Administration Medical Center applied for, and was designated by the National Institute on Aging as, an Alzheimer's Disease Research Center. The center performs basic science and bio-medical research but has no health services interventions.

GSH&MC's interest in the demonstration project was a natural extension of its previous commitment to serving Alzheimer's patients and their families. GSH&MC had found that, despite the prevalence of Alzheimer's disease and related disorders, victims of dementia were seldom singled out for case-managed community-based care demonstrations. More often, these individuals had been minimally included in larger groups of the physically impaired or mentally ill. GSH&MC felt that such general and unstratified groups have failed to recognize the unique

characteristics of Alzheimer's patients whose care requires medical and functional management as well as the maintenance of the family support system. Furthermore, while the Portland area was generally considered to be resource rich in terms of community-based services such as adult day health, support groups, and home care, these services were often expensive and uncoordinated. GSH&MC's experiencewas that families of Alzheimer's victims tended to seek services too late or not at all.

GSH&MC's objective in applying for the demonstration project was to develop a coordinated care system that: (1) linked the family with needed services and maintains its ability and commitment to care for the Alzheimer's patient; 2) integrated health and social services into a cohesive system; 3) empowered families in the management process of the disease; 4) improved quality of care for the Alzheimer's clients; and 5) facilitated communication and networking within the formal support system.

The program operated out of one of the buildings in the GSH&MC complex, which housed the key program staff including: the MAP project director; the clinical operations manager (who is responsible for supervising the case managers and service delivery component of the project); the case managers, the intake workers, and support staff. On the project part-time were two members of GSH&MC who filled project-specific roles—a planner and a financial accountant. The project and the staff were guided by a Technical Advisory Committee, which was composed of members of the medical and social service provider community as well as researchers from the University.

The catchment area served by the demonstration encompassed all of Multnomah, Washington, and Clackamas counties and portions of Columbia County. The catchment area was selected to include both urban and rural areas to provide the project with greater opportunities to test outreach strategies and service delivery systems.

For the demonstration, the client caseload was calculated by basing treatment group distribution on population statistics. In 1987, the population over 65 years of age in each of the catchment areas was: Multnomah County 81,442; Washington County 25,187; Clackamas County 28,070; and Columbia County 2,840. Using national estimates that 15 percent of the elderly over the age of 65 had dementia and 85 percent of this number are cared for in the community, it was projected that there would be 17,838 eligible participants for the demonstration project. Oregon's initial project census was 600 (300 treatment group clients and 300 control group members). The project was able to meet its original goal by April 30, 1991. On that date, there were 303 active treatment group clients.

The Community Long Term Care Service System

Oregon's Senior Services Division managed all of the state's community and institutional care for the elderly including Medicaid, a home and community-based services waiver program, a state-funded home services program, and the Older Americans Act. The Area Agencies on Aging administered the programs locally. In general, the greater Portland area was thought to be resource rich with a broad array of community-based services available including housing arrangements ranging from housing with minimal services to nursing care in non-institutional settings.

Service Provider Contracts

Although GSH&MC had the capability of providing most of the services offered by the demonstration program, it was not the principal service provider for demonstration clients primarily because of the broad catchment area served by the demonstration. The only two services which GSH&MC provided directly were companion and companion for caregiver education and

training. Beyond this, all other demonstration services were contracted out to 22 service provider agencies. The number of contracted service providers by type of service were:

Service	Number of Contracts
In-home Services	7
Adult Day Care	4
Equipment/Supplies	2
Mental Health Counseling	3
Transportation	2
Education/Support	4

COMPLIANCE WITH THE CASE MANAGEMENT MODEL

It took the Oregon project a full year to reach its case management ratio. Then, in February of 1991, the case manager-to-client ratio had become somewhat higher than the model guidelines (with the exception of the month of May), which indicates that, on average, the case manager was able to spend slightly less time case managing each client than specified in the model. However, it should be noted that sites were permitted a 5 percent variance over or under their specified case manager-to-client ratio each month in Model A sites (95-105 clients). Since the Oregon staff had two full-time and two part-time case managers, they were potentially able to minimize the impact of having a slightly higher ratio of clients per case manager than specified in the model.

Memphis, Tennessee - Northeast Community Mental Health Center

The Alzheimer's Consortium, which sponsored the Medicare Alzheimer's Disease Demonstration, was comprised of 17 health and social service providers serving a four-county area in southwest Tennessee. These agencies, under the leadership of the Delta Area Agency on Aging (DAAA), had worked together in various combinations on past projects. For the demonstration, the agencies' strengths, experiences, and resources were brought together to address a commonly perceived lack of services specifically targeted to Alzheimer's victims and their families. Collectively, the consortium was a unification of urban and rural efforts, bringing together as one unit the agencies which provided the vast majority of all services delivered to elderly persons in the catchment area.

The Northeast Community Mental Health Center (NECMHC) was chosen as the lead agency by the consortium members based on its previous experience in grantsmanship and its experience with the target population for the demonstration. NECMHC is a fully licensed community mental health center providing a wide range of mental health services to a catchment area of approximately 200,000 individuals. The Center had an extensive geriatric program, with approximately 300 clients regularly seen for counseling. In addition to NECMHC, four other key participants in the consortium provided services to demonstration project clients.

Alzheimer's Day Care was a nationally recognized program formed in 1983 in Memphis providing a day care and respite program for up to 50 Alzheimer's victims and their families. Alzheimer's Day Care, which combined extensive work by volunteers from Alzheimer's families with professional staff, was a unique public-private partnership with the City of Memphis.

The Memphis Area Chapter of the AA served a five-county area in west Tennessee including the initial four county demonstration catchment area. The Memphis chapter organized and trains local professionals, provided information to the public about service availability, supported legislation to help the target population, and worked closely with local mental health centers and nursing homes providing services to Alzheimer's victims.

Metropolitan Inter-Faith Association (MIFA) was an ecumenical non-profit agency which sponsored 27 programs directed towards providing volunteer coordination, self-help for the able, support services for the frail, and emergency services for those in crises. More than half of MIFA's programs included services for the elderly. Within the demonstration catchment area, MIFA provided extensive services in three areas: transportation, meals on wheels, and congregate meals.

Senior Citizens Services (SCS) was a non-profit social service agency with an emphasis on programs designed to delay institutionalization and promote independence. SCS operated the state Medicaid waiver program (Home Care Option for Medicaid Eligibles) and conducted other demonstration projects which gave the organization considerable experience with different types of case management models. The case management component of the demonstration project was subcontracted to SCS.

The demonstration project was located in a small commercial office on the outskirts of Memphis and housed key program staff including the MAP project director, the financial administrator, the MIS administrator, and the intake staff. The case management staff, including the case management supervisor, maintained their offices at SCS, the agency which the MAP project subcontracts with for case management services. The decision to have case management staff offices at SCS rather than in the MAP demonstration project offices reflected the MAP project director's desire for the case managers to have access to, and develop working relationships with, the large case management staff at SCS who had already developed extensive community networks on other projects.

The catchment area served by the consortium encompasses both urban and rural counties. Based on 1989 census data, population figures for the target counties were: Shelby County 777,113; Fayette County 25,930; Lauderdale County 24,555; and Tipton County 32,930; for a total of 859,903. With approximately 15.6 percent of the population of Tennessee 60 years of age and over, the estimated number of elderly in the catchment area were: Shelby 72,654; Fayette 3,222; Lauderdale 3,464; and Tipton 3,751. Although the total number of clients with Alzheimer's and related disorders that were served by consortium agencies in 1988 was only 535, the consortium felt this number was not reflective of the potential number of clients who could appropriately benefit from expanded availability of services in the catchment area.

The demonstration project proposed an original program census of 840 individuals (600 from the urban catchment area -- 300 treatment group members and 300 control group members) and 240 from the rural catchment area (120 treatment group members and 120 control group members). This goal was subsequently revised (lowered by 240 clients) and the new census goal was set for 600 clients at the end of the caseload build-up phase on April 30, 1991. On that date, the demonstration had 597 active clients (301 treatment clients and 296 control group members), which was just three clients short of their census goal.

The Community Long Term Care Service System

The catchment area was the Memphis Delta Planning and Service Area in the southwest corner of Tennessee, encompassing one large urban and three rural counties. Shelby County includes all of the greater Memphis metropolitan area and had a population of well over a million people with a wide range of medical, human, and social services available within close proximity. The three surrounding counties in the catchment area (Lauderdale, Tipton and Fayette counties) are almost exclusively rural in nature with a much more limited pattern of services and health resources available.

In both the urban and rural areas, integrative services including case management and geriatric assessment were reportedly not well developed. In the urban county, home health care services received relatively high ratings, but were less available and accessible in the rural counties. A similar pattern was reported for home support services with the rural counties having fewer services available especially transportation and homemaker/chore and personal care services. In both the urban and rural counties special purpose services were relatively poor. Notably, none of the counties had any day health care available and the rural counties also had no hospice or social day care.

Demonstration Service Providers

As the program developed and the need for specific services became clear, there were four consortium member agencies that provided direct services to treatment clients. The service provider consortium members and the services they provided are listed below.

Consortium Member	*Type of Service*
Alzheimer's Day Care	Day Care
Metropolitan Inter-Faith Association	Meals Transportation
Northeast Community Mental Health Center	Mental Health Counseling Family Counseling
Senior Citizens Services	Case Management Homemaker/Housekeeping

The majority of the services provided to the demonstration treatment clients were provided by non-consortium member agencies with whom the demonstration contracted for direct service provision. The contracted service providers and the services each agency provided for the demonstration are listed below.

Non-Consortium Member	*Type of Service*
Allied Medical	Adaptive Equipment Medical Supplies Medical Equipment Consumable Care Goods
Kirby Pines	Adult Day Care
Medical Personnel Pool	Skilled Nursing Home Health Aide Personal Care Housekeeping Companion
Partners for Service	Skilled Nursing Home Health Aide Personal Care Housekeeping

	Companion Adaptive Equipment Medical Supplies Medical Equipment Consumable Care Goods
ProCare	Home Health Aide Personal Care Housekeeping Companion
Trinity Health Care	Skilled Nursing Home Health Care Personal Care Companion

During the early phases of the demonstration, the project had considerable difficulty signing contracts with a sufficient number of home care agencies to meet the need for services. These provider problems, which largely reflected a shortage of adequately trained staff in the agencies, were resolved by the time the program reached steady-state.

Compliance with the Case Management Model

It took the Tennessee project nine months to reach the 1:100 case management model. Prior to October of 1990, the case manager-to-client ratio was consistently lower than the model guidelines, which permitted case managers to spend on average more time each month managing each client than specified for Model A sites. From October 1991 to March 1991, the case manager-to-client ratio decreased again, but then after May of 1991, each case manager had slightly more cases than "ideal" for the Model A sites.

MODEL B SITES

Miami, Florida - Miami Jewish Home and Hospital for the Aged

History and Sponsorship

The MJHHA, the largest long term care facility in the Southeast with 700 residents (600 on the campus site, 100 elsewhere), sponsored the Medicare Alzheimer's Disease Demonstration project in the Miami, Florida metropolitan area. MJHHA is a comprehensive geriatric care facility. It provides community-based social and health services as well as long-term institutional care, including a special Alzheimer's unit and case management, adult day care (including Alzheimer's day care), mental health and home health care services. At the time, MJHHA had a $15 million per year budget for non-institutional services and $25 million per year for institutional services.

In the 1970's, MJHHA began developing community-based services, with day care and community mental health services. In the early 1980's, MJHHA was awarded a channeling case management demonstration contract and later developed Medicare home health. During this same period, MJHHA also developed a research institute to promote independence in the elderly population of Miami. In 1987, MJHHA began a therapeutic inpatient program for Alzheimer's victims and a community-based Alzheimer's Day Care Center. The channeling program has continued at MJHHA under funding from the State Medicaid program. It operated as it did under the Medicare demonstration except that MJHHA now uses state criteria for nursing home

eligibility. MJHHA served over 5,000 clients annually in all of its programs. This included 500 long term care beds, plus 4,500 clients in its array of community-based programs.

In addition to MJHHA's institutional and community care service capacity, it has ongoing research and education capability in the Stein Gerontological Institute (SGI). Research conducted through the SGI included environmental assessment, adaptive technology research, and robotics engineering. SGI also had full-time training staff to develop curricula and train all levels of personnel on the technological developments made by the research unit as well as on health care and gerontological issues. MJHHA operated two adult day care programs serving 80 clients per day (300/year); ambulatory health services serving 1,000 unduplicated clients per year; an Alzheimer's adult day care program serving 25 clients a day (100/year); a case management program serving over 750 active cases; a community mental health center serving 2,500 unduplicated clients per year; a geriatric residential treatment center with 70 residential beds; a congregate living facility with 124 residents; short term emergency management system serving 325 clients a year; the SGI, the Mt. Sinai/MJHHA home health agency conducting 10,886 visits per year; and the MJHHA nursing home with 397 long term care beds, 40 rehabilitation beds, a 32 bed specialty hospital, and a 29 bed Alzheimer's unit.

While MJHHA has a long-standing history of service delivery to the elderly in Miami and a well-developed system of cooperation and coordination among other service providers in the area, MJHHA staff decided to develop their proposal independently of other major health care providers as well as the local state university. This was done, in part, because a competing consortium of providers (e.g., Mt. Sinai Hospital and the University of Miami, several nursing homes and local community service providers) were also competing for the Alzheimer's demonstration.

The MAP, as it is known in the community, began as an extension of the work already being done within MJHHA. A number of MJHHA departments were utilized during the development and implementation of the MAP project, including the education department, which was a resource to MAP in organizing and training MAP staff, home health aides, as well as MAP caregivers in Alzheimer's related issues. Staff physicians and psychologists helped in the development of the MAP client assessment instrument. The MJHHA management information systems department helped select hardware and software for the MAP MIS system and then programmed it. The fiscal department handled financial cost tracking and cost reporting systems for MAP, and the public affairs department worked with MAP in developing news releases, brochures, and other publicity for the program.

The Miami MAP catchment area included all of Dade County (Miami and surrounding areas) and South Broward County (from Fort Lauderdale and south to the Dade County line). Dade county is 42 percent Hispanic and 20 percent Black whereas Broward county is mostly White. This area encompassed nearly two million people, of whom about 580,000 were over the age of 65. Some 335,000 elderly resided in Dade County; the rest lived in Broward County. There were more than 80,000 Medicare recipients in South Broward and the number is growing rapidly. Under the assumption that 4 percent of the elderly would be cognitively impaired as a result of Alzheimer's or related dementias, it was estimated, that in the Dade-Broward catchment area, at least 23,200 of those over age 65 may be suffering from some form of dementia. Based on the above estimates, the Miami MAP initial project census was 720 (360 treatment group clients and 360 control group clients). On April 30, 1991, MAP had exceeded its original project census and had enrolled 738 clients in the program (371 treatment and 367 control). MAP subsequently enrolled a total of 432 treatment participants.

The Community Long Term Care Service System

Overall, the greater Miami area was considered by service providers to be a resource rich area, especially if the individual had the money to pay for services. There were numerous health care providers, hospitals, nursing homes, and home care providers. If the individual was on Medicaid, the services were also there, although somewhat more limited in terms of accessibility, availability, and quality.

There were services in the area targeted specifically to Alzheimer's patients. These included three diagnostic and treatment centers, adult day health, respite care, support groups, SNFs with special Alzheimer's units, and adult congregate living facilities (ACLFs) that specialized in Alzheimer's disease. There was no special SNF rate for these cases. ACLFs generally got a higher private pay rate for their units. Overall, there was huge variability in quality, accessibility, and cost in the Miami catchment area. The MAP program excluded Alzheimer's cases who were living in the Alzheimer's Specialized Care Facilities since their needs were largely being met by the facility.

There were also a number of "case management" programs similar to the MAP program in the Miami area including the Community Care for the Elderly (CCE), Hospice, Elder Care programs, MJHHA's Channeling Program and Metro-Dade Elderly Services Care Planning Unit. The CCE program had case loads of 100-130 per case manager and provided seven core services: adult day care, homemaker, personal care, home health aides, transportation, meals, and respite care. The program was funded by the Older Americans Act, state general revenues and Medicaid waiver funds. The program was administered by one lead agency in Broward and one in Dade County. Each lead agency subcontracted for their services to other providers in the area. Service eligibility was based on Older Americans Act guidelines of age 60 or older and the Older Americans Act disability criteria. The MAP program considered this program duplicative case management for purposes of randomization.

The Elder Care program was funded under a Medicaid waiver at Mt. Sinai Hospital and was structured like a Social Health Maintenance Organization (S/HMO) and included community services and medical care. Patients in the program had to lock-in to their "managed" care system. Participants in the channeling program and hospice were also excluded from enrollment due to the intensity of the intervention offered by these programs. Finally, the Metro-Dade Elderly Services unit also offered case management, homemaker, and adult day care services. Anyone qualifies who met Medicaid eligibility or is medically indigent. The MAP program also considered this program duplicative of case management services.

There were three Alzheimer's diagnostic centers in the Miami area and a group practice of neurologists that did a lot of drug studies. They ran newspaper ads seeking volunteers. These programs were, in a limited sense, competing with the MAP project for participants.

The usual entry points for Alzheimer's patients into the community care system were all of the providers listed above as well as the two Alzheimer's Diagnosis Centers, the Alzheimer's Association Elder Help Lines sponsored by the Area Agency on Agency, and all the discharge planning units in the area's hospitals. The reported barriers to the system included client and family level issues such as denial of the disease and the stigma attached to it. Language and cultural barriers in the community also resulted in a "segregation" of providers, i.e., they serve particular ethnic groups. Additionally, individuals from minority groups often did not go beyond these known service providers when the service needed was not available. There was also the problem that clients often preferred to be among ethnically homogeneous groups. Miami is racially diverse with divisions within specific minority groups (e.g., about 15 percent of the Hispanics are non-Cuban; that is, they are from Central or South America). There is also white "segregation" in that

there are Jewish and non-Jewish groups. Finally, there was some inequity in its geographic distribution of services. Everything was not equally available throughout the catchment area.

Demonstration Service Providers

Case management was an integral component of both the inpatient and community-based MJHHA programs. MJHHA operated two day care centers plus a special Alzheimer's Day Care program. MJHHA contracted with 40 different providers, often for multiple services, in Dade and Broward Counties to provide the following services:

- case management (exclusively MJHHA/MAP staff)
- skilled nursing (4 contracts-including 1 with MJHHA)
- therapy (physical/speech/occupational) (4 contracts including 1 with MJHHA)
- home health aide (3 contracts-including 1 with MJHHA)
- homemaker/personal care (7 contracts-including 1 with MJHHA)
- housekeeping (2 contracts)
- adapt/assist equipment-physical (4 contracts)
- adapt/assist equipment - cognitive (5 contracts)
- medical supplies (5 contracts-including 1 with MJHHA)
- durable medical equipment (2 contracts)
- consumable care goods (3 contracts)
- mental health (psychosocial evaluation) (2 contracts)
- chore services (general/repairs and maintenance) (3 contracts)
- transportation (1 contract)
- home delivered meals (5 contracts)
- family counseling (2 contracts)
- adult day care (14 contracts-including 3 with MJHHA)
- companion for caregiver education/training (8 contracts-including 2 with MJHHA)
- medical assessment (1 contract with MJHHA).

The project director for MAP was responsible for negotiating the contracts needed within the catchment areas. Generally, the demonstration project was matching each service provider's prevailing rate. However, several of the providers were willing to negotiate a slightly reduced rate with the MAP project. MAP elected to deal with providers with whom they had had previous experience in Dade County but had to find providers in Broward. While the rates were individually negotiated with the providers, the competition among the providers was so intense that they did not find it necessary to go out for bids.

There were some minor service delivery problems encountered by MAP during the program implementation phase of the project. The MAP program found that there were some access problems in South Broward County for day care due to the lack of an Alzheimer's specific program. A second problem concerned home health aides. The home health aide employee population in Dade county is primarily composed of minorities including Hispanics, Haitians and Jamaicans. When the program did their initial training, many of the aides did not comprehend English, so simultaneous translations of the training were provided in Spanish. While the biggest problem the program was having with the aides was a language barrier, they were also having problems with aides not showing up for work or not showing up on time. There were also some

racial and cultural problems from the point of view of the clients, who were predominantly white. Additionally, finding aides at special hours, such as nights or weekends, was very difficult.

Compliance with the Case Management Model

For 4 of the 17 months of the caseload build-up phase, the Miami demonstration was in compliance with Model B case manager-to-client ratio. During the rest of the caseload build-up phase, the Miami site case manager-to-client ratio was above the 1:30 model. This meant that for most of the caseload build-up phase, Miami case managers were spending less than the targeted 5 to 5 1/2 hours in case management activities with clients.

St. Paul, Minnesota - Amherst H. Wilder Foundation

The Minnesota Alzheimer's Consortium, which sponsors the MAD, was comprised of four organizations: the Amherst H. Wilder Foundation; the Metro-Minneapolis/St. Paul Chapter of the Alzheimer's Association; the Ebenezer Society; and the Miller-Dwan Medical Center. The Amherst H. Wilder Foundation, the lead agency in the consortium, is a large foundation with over 80 years of experience promoting the social welfare of persons residing in the greater St. Paul metropolitan area. While the Foundation has a large private endowment for program development and funding of some special programs, the Foundation is also a non-profit service provider to more than 23,000 individuals. The Elderly Division, the largest component of the foundation, offered a continuum of services including nursing homes, senior housing, and community-based long term care programs.

The Metro-Minneapolis/St. Paul Chapter of the Alzheimer's Association was a founding member and one of the largest chapters in the National Alzheimer's Association with over 1,839 active members. The chapter has generated a number of Alzheimer's related initiatives. It sponsored 45 family-oriented support groups throughout the State and conducted numerous seminars and workshops in the care of persons with dementing illnesses.

Ebenezer Society is a major provider of senior services in the greater Minneapolis area. Founded in 1917, Ebenezer has broad experience in service provision for the impaired elderly including four nursing home facilities, seven senior housing facilities, and an array of community-based long-term care services. Ebenezer also received an National Institute for Mental Health grant to publish a 13-part series on human development and aging, with special attention given to the effects of dementias.

Miller-Dwan Medical Center, through its subsidiary Quetico LifeCare Corporation represented the rural component of the Minnesota Consortium. As the leading regional specialty hospital in the Duluth area, Miller-Dwan offered one of the few rural-based Alzheimer's programs in the nation. Its Alzheimer's Residential Care program has been cited as a national model in the care of Alzheimer's victims who are unable to live at home but need 24-hour supervision.

The Minnesota Alzheimer's Consortium, the partnership developed to sponsor the Medicare Alzheimer's Demonstration, was the result of a number of Minnesotans involved at the national, state, and local level in health care related issues who had for a number of years been looking for a mechanism to develop community-based services for individuals and the families of individuals with Alzheimer's disease.

At the national level, members of the local Alzheimer's Association, served on the board of the National. At the state level, the governor had an Alzheimer's task force which prepared a report on the need for services, but had no money to implement the recommended service system. At the local level, in the St. Paul area an innovative organization, the Alzheimer's Care Network, had

been formed as a prototype for developing a continuum of care for both the client and the caregiver. Also at the local level key individuals at Wilder Foundation, Alt Care Corporation (a joint venture between General Mills and Wilder Foundation designed to foster the development of health care innovations), and the local chapter of the Alzheimer's Association had been having a number of formal and informal discussions about how to develop a better system of care for Alzheimer's victims and their families.

When the demonstration RFP was issued, and after reviewing the basic requirements, it was decided that it would be difficult to obtain the number of demonstration clients needed in the time period specified and to run an efficient system if there was only one site in the St. Paul area. At that point the key actors from the St. Paul area organizations began looking for potential partners. Ebenezer Society was approached because of its service provider reputation in the greater Minneapolis area and it had earlier contacted the Alzheimer's Care Network about replicating that program in Minneapolis. The RFP also appeared to be requesting a rural constituency and both Wilder Foundation and Ebenezer Society serve metropolitan areas. At that stage, the director of the Alzheimer's Residential Care Homes in Duluth, who is affiliated with the Miller-Dwan Medical Center which services the rural greater Duluth area, was approached as a potential partner in the demonstration. After several meetings it was agreed that a consortium would be formed with Wilder Foundation playing the lead role, both in the development of the RFP and in the implementation and management of the demonstration project.

The program operated out of four different physical locations but served only three distinct catchment areas. The Wilder Foundation housed the principal administrative and fiscal staff, including the demonstration's project director, the Wilder site director, the fiscal manager, and the case management supervisory staff as well as the site's own project director and the case management staff for those clients being served in the greater St. Paul catchment area (including Ramsey County, Dakota County, Washington County, and Anoka County). Ebenezer Society housed its site director and case management staff for clients residing in the greater Minneapolis catchment area (Hennipen County). Miller-Dwan housed its site director and case management staff for clients served in the rural area surrounding and north of Duluth (St. Louis County). All of the demonstration's direct services (e.g., home health aides, homemakers) were provided directly by or under contract with Wilder, Ebenezer, and Miller-Dwan. Finally, the Metro-Minneapolis/St. Paul Chapter of the Alzheimer's Association housed the program staff responsible for managing and conducting the demonstration outreach and intake activities (with the exception of one Intake Worker located in Duluth, but supervised from the central office). The Alzheimer's Association was also responsible for training functions and the grievance procedure.

The catchment area served by the consortium encompassed six Minnesota counties including urban, suburban, and rural areas. There were an estimated 227,605 non-institutionalized elderly in the catchment area. Under the assumption that 4 percent of the elderly would be cognitively impaired as a result of Alzheimer's or related dementias, it was estimated that 9,104 individuals would be eligible for the demonstration.

The Minnesota Alzheimer's Consortium's initial project census was 720 (360 treatment group clients and 360 control group members). The census goals were subsequently raised to 840 for the initial caseload build-up phase which ended April 30, 1991. At the end of April 1991, the demonstration had 823 active clients (412 treatment group clients and 411 control group members). From the outset of the demonstration, the consortium has been successful with its outreach and enrollment. Enrollment during the first six quarters of the demonstration averaged between 66 and 79 new clients per month (with the exception of the summer quarter when enrollment slowed to an average of 47 new clients per month).

The Community Long Term Care Service System

Two of the consortium's catchment areas—the greater St. Paul area and the greater Minneapolis area—were generally considered by the service provider community to be resource rich. Duluth and its surrounding environs, on the other hand, is a rural area with fewer resources. On the other hand, the Duluth area is also notable with respect to its model program for residential care which provided foster care specifically targeted to persons with Alzheimer's disease. The need for this type of care, however, reportedly outweighed its current availability in the Duluth area.

Services Provided By Consortium Members

Three members of the Minnesota Alzheimer's Consortium had extensive prior experience providing a range of community-based services to the elderly: Wilder Foundation; Ebenezer Society; and Miller-Dwan Medical Center. These three organizations provided the majority of the waivered demonstration services. Listed below are the demonstration services provided by each of these consortium members.

Ebenezer Society

Skilled Nursing
Physical Therapy
Occupational Therapy
Home Health Aide
Homemaker/Personal
Medical Supplies
Consumable Care Goods
Companion
Adult Day Care
Home Delivered Meals
Adaptive & Assistive Equipment
Durable Medical Equipment
Mental Health

Generations

General Chore (security locks door alarms, ramps, etc.)
Transportation
Family Counseling
Companion For Education

Wilder Foundation

Skilled Nursing
Physical Therapy
Occupational Therapy
Home Health Aide
Homemaker/Personal Care
Chore
Companion
Transportation
Adult Day Care
Home Delivered Meals
Companion for Education

Home Health Aide
Adaptive Equipment
Medical Supplies
Consumable Care Goods
Companion
Transportation

Service Provider Contracts

At each location, the consortium's sponsoring agency (Wilder Foundation, Ebenezer Society, Miller-Dwan Medical Center) was the primary and "preferred" provider of services. When possible one of the consortium agencies provided the services, but there were a number of circumstances where subcontracts were negotiated with agencies outside the consortium. The primary reasons for subcontracting were: the sponsoring agency did not offer the service; the client already had an ongoing relationship with another provider; the client lived in an area where the service is geographically more accessible through another provider; subcontracting made it possible to more quickly access services for clients; and subcontracting to maintain the referral relationship with a service provider. The project director for each location was responsible for negotiating the contracts needed within the catchment area. Generally, the demonstration project matched each

service provider's prevailing rate. However, several of the project directors negotiated slightly reduced rates for some services.

The one difference which stands out between the catchment areas with respect to service provider contracts was the actual number of contracts at each location. At the end of April 1991, Miller-Dwan Medical Center had six service provider contracts, Wilder Foundation had 68 service provider contracts and Ebenezer Society had 83 outside service provider contracts. A fair number of the subcontracts negotiated through Ebenezer and Wilder were subcontracts for a provider to service one individual in the project. The case managers were responsible for quality control with all service providers.

Compliance with the Case Management Model

To be in compliance with the 1:30 case management model in the Model B sites, the case managers should have spendt an average of between 5 and 5 1/2 hours per month per active client. During the first two quarters of the demonstration at all three locations, the case manager-to-client ratio was even lower than 1:30; each case manager was spending more than 5 1/2 hours per client per month. The project did not consistently comply with the case management model until January 1991, and even after that period of time, there are several months where the case manager-to-client ratio was either somewhat high or low depending on site location.

Cincinnati, Ohio - Cincinnati Area Senior Services, Inc.

The Medicare Alzheimer's Disease Demonstration in the greater Cincinnati region of Ohio was a cooperative effort of a consortium of five Cincinnati area health and social service providers: Cincinnati Area Senior Services (CASS); Senior Citizens of Northern Kentucky (SCNK); United Home Care (UHC); the Greater Cincinnati Chapter of the Alzheimer's Association; and the University of Cincinnati Medical Science Center.

CASS, has primary responsibility for overseeing the organization, administration, and conduct of the demonstration. The largest and oldest private non-profit agency in Hamilton County serving an exclusively older population, CASS currently provided in-home assessments, home delivered meals, financial management, case management for homebound individuals, adult day care, shared housing, multi-purpose senior centers, and adult protective services.

SCNK, a non-profit organization founded in 1962, served older people throughout an eight county Northern Kentucky area. SCNK joined the consortium in order to insure a catchment area large enough to meet the project's target enrollment and in order to include families in the demonstration who live in Kentucky but work in Ohio. Services provided by SCNK included: meals on wheels, transportation, homemaker, lifeline, adult protection, home repair/weatherization, nursing home ombudsman, senior centers, Retired Senior Volunteer Program, adult day care, and information and referral.

UHC, a Medicare/Medicaid certified non-profit agency, provided homemaker, personal care, visiting nurse, chore and respite care services in ten counties in Ohio and Kentucky. UHC also had a respite care program specifically designed to serve clients with Alzheimer's disease.

The Cincinnati Alzheimer's Association Chapter, founded in 1983, focuses on education and family support programs including a network of 14 family support groups, a quarterly newsletter, and working with area service providers who can assist Alzheimer's families. For the demonstration, the Alzheimer's Association provided educational and support services for project staff and families of clients.

The University of Cincinnati Medical Science Center, through the College of Medicine and the College of Nursing and Health, had developed a number of specialized programs related to the care of patients with dementia, including an Alzheimer's Research Center and an Evaluation and Treatment Center with an experienced geriatric medicine, nursing, social work, and psychiatry faculty. The participation of the medical center provided the demonstration access to expert clinical consultations for treatment group clients, if needed. In addition, faculty provided consultation and education programs to both the project staff and the formal and informal caregivers of the clients.

A Demonstration Advisory Committee, composed of key representatives from each of the five consortium-member organizations, guided the implementation of the project. The consortium of agencies felt that CASS was the most appropriate and experienced case management agency to serve as the host agency for the demonstration. Demonstration project staff were employees of CASS with the project operating as a separate division of the organization.

The five members of the consortium viewed the demonstration project as an opportunity to: (a) identify the strengths of the participating organizations with regard to working with Alzheimer's families; (b) establish closer working relationships between the five consortium members; (c) develop innovative outreach efforts that would identify previously unidentified victims of Alzheimer's disease and related disorders; (d) develop needed service packages without the usual financial limitations; and (e) develop cost-effective strategies for caring for clients with progressive dementia and their families.

The program operated out of one central office building which also housed the lead consortium agency, CASS, as well as the greater Cincinnati Alzheimer's Association. The office was located near downtown Cincinnati within four miles of all consortium members' offices. All administrative, financial, outreach and intake, and case management activities were performed out of the central office. Program administration, financial management, intake and case management activities were all performed by project staff specifically hired for the demonstration but working under the CASS umbrella organization. Direct services (e.g. home care, companion) were provided under contract by either consortium members or other service provider agencies in the area.

The catchment area served by the MAP Demonstration had a heavy concentration of elderly persons. In 1985, in the Cincinnati Standard Metropolitan Statistical Area, almost 12 percent of the population was over 65. In Hamilton County the population over 65 was 13 percent, and within the city of Cincinnati, 14.5 percent were over age 65. The over 65 population in the Greater Cincinnati area served by SCNK numbered 52,776. In total, the catchment area included 171,972 elderly in four counties. Using a conservative estimate of 4 percent of the population over age 65 with a diagnosis of Alzheimer's disease or related disorders, it was projected that the catchment area included approximately 6,878 individuals affected by the disease.

Based on the above estimates, the project proposal emphasized the consortium's confidence in their ability to identify 500 families (250 treatment group and 250 control group members) who would participate in the project. The census goals for the original caseload build-up phase of the project ending April 30, 1991 were subsequently raised to 600 (300 treatment group and 300 control group members). On that date, the project had 303 active treatment group clients and 294 control group members.

The Community Long Term Care Service System

The catchment area for demonstration services included all of Hamilton County in Ohio and Kenton, Campbell and Boone Counties in Northern Kentucky. Together the catchment area encompassed the concentrated metropolitan portion of the Greater Cincinnati region. In Ohio, the

long term care service delivery system is characterized by numerous non-profit social service agencies with historical roots in the neighborhoods and churches of the 32 cities in the catchment area. The Area Agency on Aging concentrates on senior centers, the Senior Olympics, the Senior Art Show, and employment programs. In 1987, the local Council on Aging also assumed responsibility for managing Ohio's nursing home pre-admission screening program for individuals who are Medicaid eligible. Within the Ohio catchment area, there are many nursing homes and retirement communities. According to community spokespersons, it is not uncommon for Northern Kentucky families to place a family member in an Ohio nursing home because of the long wait and lack of available beds in Kentucky. Over 40 different agencies serve some segment of the elderly population in Hamilton County, Ohio. CASS, the sponsoring agency for the MAP demonstration, is the largest, most comprehensive senior service agency in Ohio offering a broad range of community based services (e.g. senior centers, home meals, transportation). It is also the only private adult protective services agency in the area.

Kentucky has a streamlined system of services to the aging centralized within one agency, SCNK. SCNK is comparable to Ohio's CASS agency in that it provided a broad range of community based services for the elderly. Kentucky also has had a statewide Medicaid waiver program since 1988 which provides in-home services under the direction of certified home health agencies. In addition the state has funded a home care program since 1985 which utilized independent case management to coordinate services designed to delay nursing home placement. A moratorium on new nursing home beds in Northern Kentucky made it increasing difficult to place elderly people in institutional care. In both Ohio and Kentucky, service coordination and referral among agencies were reported to be generally good. Overall, the Greater Cincinnati catchment area served by the demonstration was generally considered by the service provider community to be resource rich.

Services Provided by Consortium Members

A number of the services offered under the demonstration were provided by one of the MAP Consortium members. The types of services provided by consortium members are outlined below:

Consortium Member	Type of Service
CASS	Companion/In-Home Respite Home Delivered Meals Adult Day Care Companion/Education & Training
SCNK	Housekeeping/Grocery Shopping Transportation Home Delivered Meals
UHC	Skilled Nursing Home Health Aide Homemaker/Personal Care Housekeeping/Grocery Shopping Chore Services Companion/In-Home Respite Companion/Education and Training
Alzheimer's Association	Education and Training
University of Cincinnati Geriatric Evaluation Center	Education and Training

Demonstration Services Provided Under Contract

In addition to consortium members, the following services were provided to demonstration clients under contract with other community service providers:

Service Type	Number of Subcontracts
Adult Day Care	(8 subcontracts)
Home Care	(28 subcontracts)
Meals on Wheels	(2 subcontracts)
Transportation	(2 subcontracts)
Medical Supplies and Equipment	(7 subcontracts)

There were two major reasons for subcontracting for services. First, if a consortium agency did not have the capacity to provide the service, it was contracted to one of the community providers. Second, depending on the location of the clients home, one of the contractors was selected as the preferred provider due to geographic proximity (e.g., adult day care).

Compliance with the Case Management Model

From the onset of the project through October 1991, the case manager-to-client ratio was within the acceptable range for a 1:30 model. It should be noted that sites were permitted to be slightly over or under the desired ratio by 5 percent (i.e. ranging from 28 to 32 clients per case manager). After

that period there was slightly more fluctuation in the ratio. During four of the remaining months of caseload, the case manager-to-client ratios were slightly higher than specified by the model.

Parkersburg, West Virginia - Wood County Senior Citizens Association, Inc.

History and Sponsorship

Two agencies sponsored the Medicare Alzheimer's Disease Demonstration in West Virginia. One is the Wood County Senior Citizens Association (WCSCA) in Parkersburg, and the other is the Family Service - Upper Ohio Valley, in Wheeling, West Virginia. WCSCA began the initial enrollment period serving one rural county area encompassing the county seat of Parkersburg (Wood County) on the far northwestern border of the state. Family Service served three rural counties (Ohio County, Marshall County, and Brooke County). These are located in the panhandle of northwestern West Virginia (situated between Pennsylvania and Ohio along the Ohio River). The service areas were expanded five times during the initial enrollment build-up phase.

WCSCA was established in 1975 as a senior recreation program. Over the years, the programs have been expanded to encompass recreation, personal and home health care, and other support services including transportation, homemaker services, escort, shopping, health monitoring, information and referral, visiting reassurance and outreach, and adult day care programs. WCSCA facilities also housed the Older Americans Act III-C Nutrition Program for the elderly. WCSCA serveed as the focal point for most senior services in Wood County. The Association coordinated social activities, special programs, and health services at 12 satellite centers and 7 nutrition sites throughout the county. In 1985, WCSCA became one of the first agencies in the state to develop and implement an adult day care program for the frail elderly. Although the adult day care program was not limited to patients with Alzheimer's disease or related disorders, the program offered specialized activities, supervision and programming for these clients. In 1989, WCSCA completed renovations within its senior facility to provide special housing for older adults in jeopardy of institutionalization.

Family Service -Upper Ohio Valley was a non-profit social service agency established in 1909. In addition to being a licensed mental health facility, it was an accredited member of Family Service Association of America, National Foundation for Consumer Credit Counseling and United Way of the Upper Ohio Valley and certified by Housing and Urban Development as a Comprehensive Housing Counseling Agency. Family Service has two divisions of programs, the Senior Services division and the Counseling division. Senior Services represented a diverse and highly specialized system of program and services. For example, in addition to providing the numerous support services offered by Wood County, Family Service has drawn upon its counseling division to provide group and individual psychotherapy, family life education, conservator services, housing counseling, and debt counseling and disbursement services to the elderly. With over 90 years of community service, 15 of which have been specific to the senior population, and with specialized programs such as Adult Protective Services, adult day care, counseling, conservator services, Family Service gained extensive experience with the community-based long-term care population.

There was no formal relationship between WCSCA and Family Service prior to the request for proposal RFP from HCFA and this was the first joint venture between the agencies. Wood County originally contacted Family Service to explore a combined application. After discussions began between the agencies, information and support were sought by the two agencies from other social and health providers within the two catchment areas. For example, the Mid-Ohio Valley Health Department, which is a regional health care provider serving a six county area in the western portion of West Virginia that provides home health services, personal care/homemaker services, and operates a hospice program was very supportive of the proposal and provided statistics to the two agencies for the development of the proposal. It was eventually selected as a

contract service provider to the demonstration. Similarly, the Ohio County Area Agency on Aging in Wheeling was brought in by Family Service to assist in information gathering, provide background statistics and service information for the proposal, and to help generate support for the program among other local service providers.

The administrative staff at both agencies viewed the proposal as a joint venture with administrative and budgetary responsibilities shared between them. In addition, both agencies realized that they needed a larger catchment area than their individual service areas if they were to meet the demonstration enrollment requirements. The approved proposal established essentially dual service systems in each separate service area. The agencies saw themselves as partners. As a result of the need for one agency to be fiscally and administratively responsible for the program, WCSCA became the lead agency.

The demonstration in Parkersburg operated as a separate unit or division within the host agency, the WCSCA. The demonstration utilized the host agency auditor, but hired a own lawyer and computer support staff. The demonstration was treated like all other divisions within the agency. Wood County's Director served the same role for all divisions within the organization: that of oversight, administration and public relations. The director of the demonstration was responsible for the day-to-day management of the program. In Wheeling, the demonstration was more closely tied into the host agency's other programs. The Wheeling Site Director reported directly to both the host agency Director and to the Demonstration Project Director in Parkersburg. Most staff were hired for the demonstration including two key staff members, the demonstration Site Director (Parkersburg) and the Case Management Supervisor (Wheeling

The catchment area served by WCSCA (i.e., Wood County) included primarily rural areas with an estimated population of over 12,000 people 65 or older. The catchment area served by Family Service included three rural counties (Ohio, Marshall, and Brooke counties) with an estimated 65 and over population of 17,820 (9,430 in Ohio County, 4,880 in Marshall County, and 3,510 in Brooke County). Under the assumption that 4 percent of the elderly would be cognitively impaired as a result of Alzheimer's or related dementias, it was estimated that approximately 480 elderly in Wood County and 713 elderly in the three counties served by Family Service would be eligible for the demonstration.

As of the 1980 Census, the state of West Virginia has the eighth highest concentration of older persons in the country. Over 12 percent of Wood County's, over 15 percent of Ohio County's, and over 11 percent of Marshall and Brooke Counties' populations are 65 or older. In addition, almost 5 percent of Wood County's, over 6 percent of Ohio County's, and over 4 percent of Marshall and Brooke Counties' populations are 75 or older. Over 13 percent of the population 65 or older in Wood County and almost 29 percent of those 65 or older in Ohio County live below the poverty level while over 15 percent of those 65 or older in Marshall County and almost 14 percent of Brooke County residents 65 or older live below the poverty level. Finally, 80 percent of those 75 or older in Wood County, 63 percent of Ohio County, 65 percent of Marshall and over 70 percent of those 75 or older in Brooke County lived below the poverty level and were living alone.

The West Virginia Alzheimer's Disease Demonstration initial project census was 240 (120 in Treatment and 120 in Control). Each site matched the treatment client census with an equal number of control group clients. The original census goals were raised 120 cases in May 1991 (60 Treatment and 60 Control) during the caseload build-up phase of the demonstration. This resulted in the final program census goal of 360 (180 in the Treatment group and 180 in the Control group) to be reached by October 1991. The enrollment figures were expanded to accommodate requests for services that originated in counties bordering the original catchment area counties.

On April 30, 1991, the West Virginia site exceeded its expanded enrollment goals and had enrolled a total of 374 clients (187 treatment clients and 187 control clients). From the outset of the

demonstration, both the Parkersburg and the Wheeling sites were successful with their outreach and enrollment activities.

The Community Long Term Care Service System

The original catchment area for the demonstration included one county in northwestern West Virginia and three counties in the panhandle of northwestern West Virginia between Ohio and Pennsylvania. The initial catchment areas included two metropolitan areas; Parkersburg (the county seat of Wood County) and Wheeling. Parkersburg served all of Wood County while the Wheeling site served the Ohio, Marshall and Brooke county areas of West Virginia.

In July 1990, the WCSCA expanded its catchment area to include four additional counties in West Virginia, including Pleasants County, Wirt County, Ritchie County, and Jackson County. The WCSCA also included the City of Belpre, situated across the Ohio River in Washington County, Ohio. In September 1990, Family Service expanded its catchment area to include two new counties; Wetzel County in West Virginia and Belmont County in Ohio. In December 1990, Tyler County in West Virginia was added to the Wood County catchment area and in May 1991, Family Service added Hancock County in West Virginia and the Stubenville metropolitan area in Jefferson County, Ohio. The total catchment area between 12/89 and 5/91 included eleven counties in West Virginia and three counties in Ohio.

The long term care service delivery system within the four counties of the West Virginia demonstration catchment area was characterized by few non-profit or for-profit social and health service delivery agencies. The counties are rural, with Columbus, Ohio the closest large metropolitan area, approximately a four hour drive from Parkersburg. Pittsburg, Pennsylvania, the next largest metropolitan area, is a three hour drive from Parkersburg and a one hour drive from Wheeling. The need for nursing home beds was critical in West Virginia since this was the traditional service option for families with an Alzheimer's patient. Few service agencies focused on Alzheimer's and the medical community tended to institutionalize Alzheimer's patients due to the dearth of community-based service options in West Virginia. In some instances, West Virginians traveled to Ohio and Pennsylvania to obtain specialized services. This was true both for Wood County and the Wheeling site.

West Virginia, like many states, d certificate of need process that limited the availability of nursing home beds. Complicating this situation even more, nursing homes had a "freeze" on the number of beds that could be "booked." Ohio and Pennsylvania tended to have more beds available due to more aggressive pre-admission screening programs that limited the number of elderly admitted to nursing homes and a broader, more comprehensive community-based long term care system.

In Parkersburg, the major community health service provider was the Mid-Ohio Valley Health Department, a regional service provider serving six counties in mid and western West Virginia (Pleasant, Ritchie, Wood, Wirt, Jackson, and Roane counties). It was the only regional health department in the state and the only health department in the state offering a home care program (i.e., personal care). Other services included a home health agency and a hospice program. Although the Parkersburg area was among the top ten within the state in numbers of people served by most programs, there were few case management and/or information and referral services in the county and few special purpose services like adult day health care. Finally, there were no respite care programs for the elderly and few special living arrangement options (such as adult foster care/board and care homes, congregate housing, senior citizen housing, nursing homes).

Since WCSCA was primarily a home and personal care provider, the idea initially was to use the host agency's homemaker service as a major contract provider. However, because the homemaker program was understaffed and because it did not want the responsibility for training or scheduling

specifically trained staff to work with the Alzheimer's cases, the decision was made to set up a separate home care department within WCSCA to serve the demonstration clients. This was done during the implementation phase of the project and the program seemed to work well. There were no internal "turf" issues between the two staffs. Additionally, the new program did not affect referrals to the original homemaker program.

The same situation was found in Wheeling and the three counties served by Family Service; that is, there were few service delivery options in northwestern West Virginia. The Wheeling catchment area contained a "panhandle," situated between Pennsylvania and Ohio. Services, especially if the client qualified for a state or federal program or could pay for it, could be obtained in any of the tri-state counties. Overall, there were access problems in all four counties for Alzheimer's patients in West Virginia. The main barrier was money and the fact that there were few services available for people with Alzheimer's.

On July 1, 1991, three case management agencies in the Wheeling catchment area assumed responsibility for the pre-screening of nursing home admissions. Hospitals in the area referred cases to one of the three agencies who did screening assessments, costing of care plans, and initiation of community services. The clients must have been medically eligible for nursing home admission and either have been financially eligible for Medicaid or pay for services on a sliding fee scale. The program was the beginning phase of a coordinated access system that had one focal point of entry.

There were very few services specifically targeted for the Alzheimer's patient in either the Parkersburg or the Wheeling areas. However, most social and health service agencies serving the elderly in the four counties had dementia clients. WCSCA started the first Adult Day Care Program in the area and, while the program served many age groups, approximately 11 of the over 35 elderly participants were Alzheimer's patients. Family Service also established an Adult Day Care program, though it, too, served the general elderly population not just Alzheimer's patients.

The usual entry point for Alzheimer's and related dementia patients was through the medical community. The AD diagnosis usually occurred in the hospital after an illness episode or accident calls attention to the case. Other entry points were the family physician and Adult Protective Services. Both the hospital and Adult Protective Services were getting advanced stage cases and were likely to refer to nursing homes. Physicians were seeing cases at a much earlier stage in their illness and did refer to community-based services where available. However, most referrals were to nursing homes or other institutional settings and there appeared to be some incidents of nursing homes refusing to accept Alzheimer's patients. Finally, there were no respite programs in the Parkersburg or Wheeling areas for the elderly.

Demonstration Service Providers

Each host agency in the West Virginia demonstration was the primary and "preferred" provider of services. Subcontracts were negotiated with agencies outside the host agencies. The Parkersburg site was contracting with most of the area's social/health providers except for durable medical equipment providers in Wood County where they have negotiated two contracts. In Wheeling, all other providers were contracted with. Overall, cooperation with other agencies, especially for referral of clients, was good in both sites. The demonstration staff believed this is a result of the recognition that services for this population were rare and that many service providers in the area did not want to deal with this population.

The primary reasons for subcontracting were: the host agency did not offer the service; the client already had an ongoing relationship with another provider; the client lived in an area where the service was geographically more accessible through another provider; and/or subcontracting

enhanced the ability of the case manager to effectively broker service on behalf of clients and caregivers. The Project Director in Parkersburg and the Agency Director in Wheeling were responsible for negotiating the contracts needed within each catchment area. Generally, the demonstration matched each service provider's prevailing rate. However, in a few circumstances, the director was able to negotiate a slightly reduced rate for some services. For the most part, the contract agencies had no problems accepting the liability for bad debt or allowing the demonstration to collect the co-payments or offering employees the special training in working with Alzheimer's and their families.

Two problems were encountered with the service delivery contracts in Parkersburg. One problem was that not all service arrangements were set up as quickly as the case managers needed them. The other problem was the lack of appropriately trained contract agency staff. Thus, service delivery in the early part of the project was about one month behind schedule.

Services provided by WCSCA included:

- adult day care,
- home delivered meals,
- transportation,
- personal care/homemaker services,
- companion services,
- chore (general and repair/maintenance), and
- caregiver education and training, and
- housekeeping services

Services provided by Family Service-Upper Ohio Valley included:

- adult day care,
- personal care/homemaker,
- housekeeping,
- companion services,
- home delivered meals,
- transportation,
- mental health services,
- family counseling, and
- caregiver education and training.

Wood County had a total of 16 service provider contracts as of April 1991 while the Family Service had a total of 18 service provider contracts. Most of the contracts were for homemaker or personal care services (seven in Parkersburg and six in Wheeling), home health agency, durable medical equipment or home maintenance services.

Compliance with the Case Management Model

During the client build-up phase, the two West Virginia locations had vastly different case manager-to-client ratios. During caseload build-up, the Parkersburg site consistently averaged a

higher than 1:30 case manager-to-client ratio while the Wheeling site fluctuated above and below the Model B ratio. The case managers in Parkersburg and Wheeling were spending less than the 5 to 5 1/2 hours per client as required in the model. Case manager-to-client ratios in Parkersburg ranged from a low of 1 case manager to 20 clients in February 1990 to a high of 1 to 61 clients in March 1991. The Parkersburg site averaged a case manager-to-client ratio of 1 to 45. Case manager-to-client ratios in Wheeling ranged from a low of 1:11 in February 1990 to a high of 1:47 in November, 1991. By June 1991, the Wheeling site was slightly under the 1-to-30 ratio. This meant that the case managers in Wheeling were spending, on average, slightly more than the required 5 to 5 1/2 hours per month per client by the end of June. The Wheeling site averaged a case manager-to-client ratio of 1:34.

Appendix Five

Guidelines and Technical Assistance in Case Management Implementation

To implement the demonstration in the context of the evaluation design, a number of decisions were made that provided guidelines to the sites for operationalizing the models being tested. Implementation issues arose in client outreach/eligibility, case management staffing patterns, minimum case management data and basic client assessment areas, client changes in status, and attrition replacement. These issues are addressed below.

CLIENT OUTREACH AND ELIGIBILITY

To mitigate against contamination of the evaluation design that could occur during the recruitment and enrollment of clients a number of basic procedures were adopted by the sites and evaluators.

Roll-over Cases

The most significant form of "contamination" in the context of this demonstration was the receipt of services equivalent to those offered through the demonstration. Receipt of such services by the control group would affect the evaluation in that, for all practical purposes, there would be no difference between the services received by the treatment and control groups. For such cases enrolled into the treatment group contamination takes another form: the presumption would be that care needs would already identified and that a care plan was in place. Demonstration benefits to this "roll-over" group would in actuality be few, but any differences between such cases and other controls would be attributed to the demonstration.

Efforts to minimize contamination began with the consideration of the question: "What is the purpose of the demonstration, to compare the effectiveness of the case management and waivered reimbursement for services against no case management and no reimbursement for services; or to compare the benefit of the demonstration's reimbursement and case management against the prevailing treatment experience in the community?" The latter purpose was deemed appropriate. As sites had no ability to control what happened to the control group or to the community service delivery system over time, the most effective time for minimizing contamination was at enrollment into the study. To accomplish this, each site identified programs in their community which were offering case management services comparable to, or more extensive than, those offered by the demonstration. Such programs included Medicaid waiver programs, other federal demonstrations, or certain specialized housing projects such as life care. Residential care housing did not automatically fall into this category. Sites were given the option to categorically exclude from the demonstration everyone receiving services from these types of programs.

The principle source of these "roll-over" cases was the home and community based care programs offered under state Medicaid program waivers. Most sites elected to exclude or greatly limit the number of Medicaid enrollees as one means of limiting this evaluation threat. A second strategy adopted by all sites was to identify applicants thought to be receiving "comparable" levels of case management and other services. This identification was made through the self-report by the applicant of the services and providers they were using. Because it was anticipated that many clients and their caregivers would not know that they were receiving case management services, since the term may be unfamiliar to them, sites were provided a script with appropriate probes so that the determination of a rollover client could reasonably be made.

Providers on the applicant's list the known to provide intensive case management or to be participating in the Medicaid waiver program were then contacted (either by program staff or the evaluators) to ascertain whether the applicant was obtaining a "comparable" level of care. The following criteria were used to assess whether a case was a rollover:

- the case had to be "open" and assigned to a case manager at the time of the demonstration intake interview;

- The case management being received had to be more than just establishing ongoing eligibility; it must be long-term; and the frequency and intensity of contact must be enough that the client (or more likely, the caregiver) knows the name of the case manager and the case manager would likely be in contact with the client (or caregiver) when assistance was needed.

If the applicant was receiving case management services similar to the demonstration intervention, then they would be considered a rollover for purposes of the rollover caps established for each site. The judgment as to "potentially" duplicative service providers was left to the case managers at each site because of their detailed knowledge of the structure of services provided in their community. A small percentage were found not to be rollovers and were taken out of that category for purposes of characterizing the enrolled sample.

Since the collection of these data occurred only after an intake interview, and assignment into the demonstration, it was necessary to limit the number of "roll-over" cases within each plan rather than to bar such cases altogether. Sites were allowed a quota of roll-over cases (i.e., 15% of their planned membership). No site reached this level.[1] This level was computed based on the total number of "non-rollovers" necessary to statistically detect the effects of the demonstration.

Another form of cases treated as "roll-overs" were those applicants who did not have an informal caregiver, either because they were responsible for their own care, or because a formal care provider (such as a live-in attendant or a residential care operator) was handling all appropriate care. The concern with these cases was that data collection assumed a competent respondent, and a large portion of the expected outcomes of the evaluation were based on caregiver affects. Multiple data points on a caregiver were needed to measure these affects. To help enable sites to more quickly reach their planned client operational levels, HCFA allowed the sites to enroll these types of cases, but included the allowable number within the sites overall quota of roll-over cases.

Service Intervention by Intake Interviewers During Enrollment

Client safety, both at the time of the evaluation intake interview and after enrollment into the demonstration, was an important concern. Guidelines were developed to assure that client needs in this area were not secondary to the implementation of the demonstration or the evaluation design. Life threatening or other emergency interventions (e.g., elder abuse, protective service, or institutionalization actions) necessary during initial contacts with the client or their families were responded to as appropriate. Any client who required interventions because of safety concerns prior to randomization was deemed ineligible to participate in the demonstration.

Client emergency or life threatening situations arising after randomization into the treatment group received whatever assistance was appropriate by either the host demonstration site or through referrals to other agencies. Among the control group, evaluation field staff were authorized to make referrals to the appropriate agencies. If such referrals came through the demonstration host agency, the sites were instructed to respond to these requests in their standard practice manner. They could not use the services of the demonstration or the demonstration case managers.

If, during the intake interview, the interviewer provided assistance to the client or caregiver (e.g., the interviewer assisted the caregiver in cleaning the client after an episode of incontinence), but there was no discussion of where to go for help with the problem and no referrals are made for

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[1]Within the months of December, January, and February 1989-90, one out of three cases submitted for randomization were allowed to be rollovers, up to a site's maximum number of allowed rollovers. If sites did not reach their rollover caps in these three months of the enrollment, they could continue to randomize rollovers into the demonstration until the caps were reached. If a rollover client left the demonstration for any reason (e.g., death, moved out of the area) after the cap was reached, the client had to be replaced with a non-rollover case.

further outside assistance, then the client remained eligible for participation. If the client or caregiver requested a referral for help, a standardized handout listing the name of the two referral sources identified by the site (i.e., an information and referral agency and the local Alzheimer's Association) was given to them by the interviewer. If in the course of providing assistance to the client or caregiver during the intake interview the interviewer found it necessary to provide information about other service providers in the community beyond that contained in the standardized handout, then the person was no longer eligible for the demonstration.

If an accident or a problem arose during the intake interview that was not an emergency but needed to be resolved before the interview could be completed, the following options were available for the intake interviewer:

- Interviewers could suggest that they would be happy to wait while the caregiver and client take care of the problem; or
- Interviewers could reschedule a time to return and complete the interview.

The critical factor in the intake interviewer's determination of whether an applicant remained eligible for the demonstration was the provision of information about service providers in the community beyond that available on the standardized handout. If any information beyond the standardized referral handout was provided, then the client was ineligible for the demonstration.

Interviewers were instructed to treat information requests for services received before or after a client was assigned into the control group in a uniform manner. All responses to such requests took the form of the standardized handout listing the names of the two identified referral sources. If information requests were directed to the site from any agency or potential applicant, they were responded to in the site's standard practice manner and did not involve the demonstration case managers. If an applicant exhibited or expressed non-emergency service needs during intake but did not request help, the interviewer did not volunteer referral information.

Sites were also instructed that, if after randomization a control group member/caregiver called the site, the client or caregiver should be treated in the site's standard manner but they remained ineligible for any demonstration services.

Diagnosis of Dementia

Clients were deemed eligible for the demonstration if their physician attested to the fact that the client had an irreversible dementia. A requirement to obtain a differential diagnosis of dementia as a condition for participation was considered but was deemed to be problematic both in terms of time and cost. With regard to cost, for example, if all of the approximately 8,000 people enrolled in the demonstration were given a comprehensive diagnostic work-up to determine eligibility, the cost would have been approximately $8 million or 20 percent of the original congressional appropriation for the entire service portion of the demonstration (assuming a conservative cost of $1,000 per client per work-up). Time limitations also would have made it impossible to complete diagnostic work-ups on all clients. For example, across California's nine specialized Alzheimer's Disease Diagnostic and Treatment Centers (ADDTCs) an average of 900 patients are assessed per year. Even if clinical facilities located in the communities of the eight sites could complete three times as many diagnostic work-ups per year than ADDTCs (i.e., 2,700 clients evaluated across all sites per year), it would still have taken over two years just to diagnose everyone enrolled in the demonstration. This length of time did not include finding cases. Because of these constraining factors, HCFA chose to rely on the patient's physician's judgments. Sites were provided with the following guidelines for a diagnostic work-up to distinguish a reversible from an irreversible dementia. The steps required to make this differentiation were as follows:

- A comprehensive history and physical
- Mental status examinations including tests such as the MMSE, a verbal fluency test, and the Blessed Orientation Concentration Test
- A DSM-III criteria checklist for depressive symptomatology such as is available on the Diagnostic Interview Schedule
- A comprehensive neurological examination
- A complete blood screen including B12 and VDRL
- An imaging procedure such as a Computerized Axial Tomography scan to detect treatable silent brain tumors or reversible hydrocephalus.

These procedures have an estimated cost of between $1,500 and $2,000 per case. Sites could implement these assessments with funding from non-demonstration sources. No sites implemented these practices.

Another issue was how a diagnosis of "non-specific" dementia should be handled in determining eligibility for the demonstration. The decision made was that since a major consideration in evaluating the eligibility of an applicant was whether the referring physician had concluded that the client had an irreversible dementia, it was not essential that they classify the dementia into a specific eligible diagnosis. When a patient had, for example, an Alzheimer's disease diagnosis (an eligible disorder) in conjunction with alcoholic dementia (an ineligible disorder) presented another special eligibility situation. The policy adopted was if the patient had an irreversible dementia diagnosis included with ineligible dementia diagnoses, the client was eligible to participate in the demonstration. Any client found after enrollment to have a reversible dementia was terminated from the study and replaced in the sample.

Changes in Client Status

A number of conditions defined a change in client status. Among these were death, entrance into a nursing home, found to have a reversible dementia, failure to pay the co-payments for demonstration services, failure to comply with demonstration services guidelines. Each of theses situations affected demonstration payment eligibility and evaluation data collection. Cases dying or permanently entering a nursing home within the first 30 days after enrollment into the demonstration were ex post facto omitted from the evaluation sample. Deaths after this baseline period where treated as an end of study event. Capitation payments to the demonstration programs ended with the last month of participation. A close-out evaluation interview was conducted with the caregiver. Nursing home admission per se did not affect the program status of the client. However, if the stay was deemed to be permanent, which it was after 60 days, the demonstration disenrolled the client. Evaluation data collection continued for up to 12 months post placement. Cases found to be ineligible because of a reversible dementia were removed completely from the evaluation data base. The client was also disenrolled from the demonstration, but without an obligation to repay any service costs. Person dropped from the demonstration for failure to meet co-payments or other requirements of the program were similarly terminated from evaluation data collection concurrent with their period of enrollment. Status changes are shown in Chapters 6 & 7.

Technical Assistance in Program Implementation

Technical assistance to the demonstration occurred in several forms and in three stages. The first stage was conducted by Mathematica Policy Research (MPR). MPR was contracted by HCFA to prepare the demonstration model, a preliminary evaluation plan, and to assist HCFA in the

selection of program sites. These activities occurred between 198x and 1989. MPR worked closely with the sites in planning their operational and staffing structure, identifying the providers who would be contracted for services, and helping to formulate an initial strategy for marketing the program.

Stage two of technical assistance was implemented by the sites themselves as they worked with local and state-wide resources to train their staffs in issues related to Alzheimer's disease and related disorders, developed management information systems for billing and expenditures reporting, and developed preliminary assessment tools and treatment protocols.

The third stage of technical assistance began with the awarding of the demonstration evaluation contract to the University of California, San Francisco in October 1989. This contract included a requirement to provide technical assistance to sites primarily in the areas of data collection and implementation of the case management models. A telephone survey with the sites shortly after starting the contract revealed a range of staff training needs, training and information needs for caregivers and in-home support staff. This was followed by periodic meetings and site visits with the demonstration programs to follow-up on specific issues and to assure that procedures were being implemented as expected.

Measurement and Assessments

Among the early common needs was better understanding of the administration and justification for certain scales used in the intake instrument--specifically the caregiver stress and burden scale, the depression scale, and the MMSE. Background information on the reliability and validity of these scales, as well as scoring and administration methods, was distributed to all sites. Additionally, the staff at each site who were to be responsible for conducting the intake interviews were trained in the use of the instrument and its scales by evaluation staff.

The Process of Case Management

Although all sites had assessment processes and protocols in place prior to demonstration enrollment, each was attempting to adjust and refine this process in light of their four months experience. The Model A sites, with one case manager for every 100 clients, had particular difficulties rationing the allocation of case management services to clients. A training and technical assistance meeting for the Model A sites was held on April 10 through April 12, 1990 in Baltimore, Maryland. Packets of information were distributed at the meeting containing a review of community-based long term care experiments to date, some resources for caregivers, an in-house review of basic principles of case management, as well as a bibliography of articles that dealt with case management or Alzheimer's disease or both. The most important outcome of the meeting was agreement about certain basic domains that had to be covered in some fashion by all case managers during client/caregiver assessment. These included: demographic information; assessment of support systems; environmental assessment; client health history; client functional assessment; behavioral assessment; legal, financial, and protective service issues; and assessment of the use of formal services.

Site visits by the training and technical assistance coordinator were conducted to help resolve the specific issues arising at the sites. These visits, involving all sites, were completed by May 1990. Among the many issues discussed at these site visits were: (a) elements that needed to be included in a care plan; (b) the most effective way to make use of nursing staff with expertise in geriatrics; (c) how case managers could provide support for clients and caregivers without finding themselves in a professional "counseling" role; (d) the possibility of using (and how should the project define) "independent contractors" as service providers for the clients; and (e) how to deal with a multi-lingual, multi-ethnic client and service provider mix.

In addition, at each site plans were reviewed for establishing caregiver education, training, and support groups and sites were invited to submit especially difficult or demanding cases for discussion and consultation.

The Model B case manager technical assistance meeting was held in Baltimore on June 13, 1990 to follow-up on questions and the problems uncovered at the site visits. Sites shared their methods of resolving these issues. Among items discussed were: (a) ways of using leverage to obtain the best services for demonstration clients; (b) identifying barriers to service utilization; (c) alternative ways of training and supporting caregivers; (d) the appropriate use of medical, psychiatric, legal and pharmacological consultants; and (e) defining what was expected by the evaluation team in terms of case documentation.

Case Management in a Steady State Program

Another technical assistance meeting for both Model A and Model B sites was held in Baltimore on March 26 and 27, 1991 was held in response to problems occurring as sites reached their full projected enrollment. An addition problem was that there were many new case management staff, either as a result of staff turnover or new enrollment levels, who had not been on board to attend previous training. This meeting covered topics such as: (a) the reasons for underutilization of services by caregivers (especially mental health services), and a discussion of how case managers could attempt to deal with this issue; (b) identifying and dealing with elder abuse and neglect including emotional, physical, and financial abuse; and (c) methods of working with families to avoid unnecessary or premature institutionalization of clients. Many site-specific issues around implementing the model were also covered at this meeting. A packet was prepared with articles and other materials for the sites.

This meeting was followed by a request from the West Virginia and Oregon sites for further assistance. A site visit was made to Wheeling, West Virginia directly following the meeting in Baltimore. One of the main issues dealt with was the appropriateness of the demonstration for treatment of extremely physically ill clients. As the demonstration was "aging," so were many of the original client intakes and the Wheeling site had a high number of clients requiring intense levels of skilled nursing in order to remain at home. The responsibilities as well as the limitations of the demonstration were reviewed. As client needs became more intense and complex, greater responsibilities and the need for excellent clinical judgment were beginning to become a necessity for case managers. Ways to upgrade the skills of current staff were discussed as well as the need for ongoing staff training and effective use of consultants and available educational resources in the area.

Later in the month a site visit was made to Portland, Oregon. Portland had an almost entirely new staff since the inception of the program. Understandably, they had many questions about implementing the 1 to 100 model and the focus was how to inform, support, and empower caregivers as the case manager-to-client caseload ratio reached the 1-to-100 objective. The assessment procedure had been revamped and streamlined and it was reviewed by the training and technical assistance coordinator during this site visit in order to determine if the essential assessment domains were still being adequately addressed.

Chart Reviews

Another aspect of the training and technical assistance involved reviews of randomly selected client charts. The first phase of this work was completed in July 1990. Each site sent in two to four charts, randomly identified by site and client identification numbers, for review. The training and technical assistance coordinator then reviewed the charts to determine if the demonstration's minimum case management standards were being met. These criteria included:

- clear definition of the presenting problem
- adequacy and appropriateness of the care plan
- the timeliness of the implementation of the service plan
- evidence in the chart of regular phone and/or in-home care monitoring of service providers
- the effectiveness of the problem-solving techniques employed
- evidence of a process for determining if case objectives were being met in a timely fashion
- the organization and completeness of the documentation

The intensity and the time spent on individual cases varied by model type, but overall it was clear that all sites were effectively meeting at least minimum, and at sometimes very high, standards for case management. Written feedback on each chart submitted for review was supplied by the training and technical assistance coordinator. The quality of case management intervention, the documentation, and the organization of the chart were all reviewed and included in the case-by-case commentary. Sites were invited to respond with comments and questions on this process, and they in general relayed that they felt it to be a positive learning experience.

Demonstration Phase-Down

The final training and technical assistance meeting was held on April 27-28, 1992 in Cincinnati, Ohio. This meeting included case managers from both Model A and B sites. Topics covered during this training included issues surrounding the demonstration wind-down and the integration of treatment group clients back into the normal community service system, methods to keep people with dementia out of institutions, maximizing appropriate use of demonstration services, and the appropriate use of support groups.

Other On-Going Assistance

Throughout the demonstration implementation, sites called in on an as-need basis (an average of about once a week across all sites) for information on program procedures (e.g., expectations of the demonstration, HCFA policies related to the demonstration), consultation on specific problems, or simply discussion on a variety of topics related to the day-to-day work in the field. Among issues discussed:

- Whether or not people with Multiple Sclerosis were appropriate for the demonstration, redefinitions of rollovers for certain cases, and determining responsibility for transporting clients when they entered or left a health facility.

- The development of appropriate criteria for the use of liquid nutritional supplements with Alzheimer's clients. Two types of indicators (medical and environmental) were developed to assist in identifying a situation where the use of a liquid diet might be considered to be an appropriate intervention for a person with dementia. These criteria were then adopted for use across all sites.

On occasion case managers have needed advice on how to deal with a difficult situation, such as how to talk to a physician when the case manager was certain that alternate types of medication were needed, or how to handle a situation where a caregiver thought she had fallen in love with her case manager. Other calls were for assistance with a particularly difficult case. Some of the more interesting consultations involved:

- The caregiver who simply left her demented husband on the front porch of the demonstration project office, phoned her case manager to tell him the client was there,

and checked herself into the hospital where her physician said she was not to be disturbed.

- The client who, although going to an Alzheimer's day care center, kept loaded guns in the house and for years physically abused his wife. This was a situation which had continued for some time in spite of regular visits from a VA psychiatrist who apparently had not seen fit to either remedy or report the situation until the case manager became involved.

- The case where, when the case manager went out to do the assessment, she realized the "caregiver" was more severely psychiatrically impaired than the client and had to make arrangements to institutionalize the caregiver before the client's needs could be addressed.

- The case where two older sisters who are in their nineties were caregivers for their youngest sister who was totally bedridden and unable to recognize her surroundings. The two older sisters had learned to provide almost a skilled level of nursing care around the clock for their youngest sister and planned to continue to do so until she died, although periodically the sister was hospitalized with bed sores.

Appendix Six

MISCLASSIFICATION AND SELECTION BIAS WHEN IDENTIFYING ALZHEIMER'S DISEASE SOLELY FROM MEDICARE CLAIMS RECORDS

By

Robert Newcomer, PhD*
Ted Clay, MS†
Jay S. Luxenberg, MD‡
Robert H. Miller, PhD*§

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*Department of Social and Behavioral Science and the Institute for Health & Aging, University of California, San Francisco; the ‡Department of Medicine, University of California, San Francisco, and the Jewish Home for the Aged, San Francisco; the §Institute for Health Policy Studies, University of California, San Francisco; †Clay Software and Statistics, Ashland, Oregon.

Abstract

Background: Medicare claims as the basis for health condition adjustments is becoming a method of choice in capitation reimbursement. Claims-based beneficiary classification for Alzheimer's disease has been found by a recent study to produce lower prevalence estimates and higher average costs than prior health care cost studies in this population. These sets of studies differ in data sources, period length, and in their specification of dementia .

Objectives: Participants in the Medicare Alzheimer's Disease Demonstration (MADDE) provide a sample of persons known to have some form of dementia. This group is used to test the adequacy of claims data for identifying eligible cases and any bias in expenditure differences between those flagged or not flagged by a claim in a given period.

Design: A prospective cohort design using up to 36 months of claims data.

Setting: The demonstration enrolled a total of 4,166 participants into treatment and 3,942 into a control group in eight communities across the US. Cases were combined in this analysis.

Participants: Persons with available Medicare Part A&B claims data--those receiving care under fee for service reimbursement were used in the analysis. A total of 5,379 MADDE cases received fee for service care during 1991 and 1992, the period of primary interest in the analysis.

Measurement: Client health and functional status interviews and Medicare Part A & B claims.

Results: Less than 20 percent of MADDE participants were classified with a diagnosis of the Alzheimer's type (DAT) from a single year of claims, this from a group where more than 68 percent had a DAT from a referring physician. Annualized expenditures were 1.7 higher among those with DAT from claims than those otherwise known to have dementia, but who had not been identified with this condition from Medicare claims.

Conclusion: Under-classification of dementia from claims records can be partially remedied by increasing the period over which claims are compiled, but additional diagnostic sources will likely be needed to increase prevalence counts closer to 100 percent of true cases. Risk adjustment based on a single year of reported claims expenditures may over pay providers the payer, at least in the short term, because payment incentives will likely increase prevalence reporting.

Introduction

The expansion of managed health care and prepaid reimbursement has heightened attention to differential health care costs among chronic health conditions. This has been motivated both by a desire to identify patients at risk for preventable high cost care, such as a hospitalization, and by attempts to translate differential cost into risk adjusted reimbursement rates. A number of investigators have given attention to costs associated with Alzheimer's disease and other forms of dementia (see for example[1-4]), but only a few of these have attempted to translate these costs into a risk adjusted rate for Medicare.[5-9] Most of this work has shown either an inconsistent relationship between dementia and expenditures over time[6] or a protective relationship in which persons with dementia had lower expenditures holding other conditions constant.[5] A recent paper by Michael Weiner and his associates at Johns Hopkins University reported that the presence of dementia of the Alzheimer's type (DAT) essentially doubled Medicare hospital and outpatient expenditures over those of the average Medicare beneficiary without dementia[9]

The difference between the Weiner and colleagues' findings and earlier studies may be attributed, in part, to variations in the chronic conditions included as co-morbidities in these analyses, or to how statistical adjustments were made for age and other health conditions in these studies. The focus of the current paper, is how the methodology used for classifying cases with conditions such as dementia or heart failure affects prevalence estimates and whether the classifications produce an observation bias in expenditure levels. Specific attention is given to the prevalence estimates obtained using claims data. The findings raise questions about the Weiner and colleagues' proposal for a 1.9 risk adjustment rate for DAT, but the broader implication is the general limitation of current claims data in classifying cases by diagnosis.

Methods

The Medicare Alzheimer's Disease Demonstration (MADDE) provides a longitudinal sample of persons known to have some form of dementia. These individuals are to test the adequacy of claims data in capturing eligible cases and the expenditure differences between those flagged or not flagged by a claim in a given period. MADDE was financed by Medicare and operated in eight communities (Champaign/Urbana, Illinois; Cincinnati, Ohio; Memphis, Tennessee; Miami, Florida; Minneapolis, Minnesota; Parkersburg, West Virginia; Portland, Oregon; and Rochester, New York) between 1990 and 1994. Eligibility for the demonstration required a physician certified diagnosis of an irreversible dementia (e.g., Alzheimer's disease, vascular dementia). Nursing home residents at the time of enrollment were ineligible. Individuals in this data base consist of voluntary applicants to the demonstration, who were then randomized into treatment and control groups. These individuals reflect a cross section of dementia cases in the late stages of the illness, but this is not a random sample of the dementia population. Persons in the treatment group were eligible for case management and limited coverage for home care, companions, personal care, adult day care and other community services under the demonstration. Both groups continued to receive their usual Medicare Parts A & B care coverage. Data collection, client enrollment, and informed consent processes were conducted in accordance with procedures approved by the Committee on Human Research, University of California, San Francisco.

The demonstration enrolled 4,166 participants into treatment and 3,942 into a control group. All cases were combined for purposes of this analysis, as the intervention had only a minor and inconsistent effect on client Medicare expenditures. Only cases having both Medicare Part A&B claims data available were used in this analysis (n=5,379). Medicare claims for these individuals were obtained for 1991 through their 36th month of participation, death, or health maintenance organization enrollment. Only individuals receiving care under fee for service reimbursement have Medicare claims records. This data limitation is common between the MADDE data set and all

other studies based on Medicare claims records. The period of primary interest in the analysis is 1991-92, a period spanning that used by Weiner and his colleagues.[9]

Results

Claims based Prevalence Estimates of Dementia. The initial study question evaluates Alzheimer's disease prevalence rates on Medicare claims records. For purposes of the current analysis the decision rules employed by Weiner and his colleagues[9] to identify cases were replicated. First, only Medicare Part A (hospital inpatient and outpatient services) and Part B (physician outpatient services) claims were used. This excluded skilled nursing, home health, and hospice claims. Cases were defined as having dementia of the Alzheimer's type (DAT) if they had a claim with an International Classification of Disease, ninth revision (ICD-9) diagnosis code for DAT (code 331.0) on at least two separate dates of service. The following codes were accepted as representing 331.0 in the data base: 331, 331.0, 3310, 331 0, and 33100.

A total of 9,323 cases were identified by Weiner and his associates from 1,221,615 in the 1992 fiscal year national 5 percent sample of Medicare beneficiaries. This estimate (0.76 percent) is substantially under dementia prevalence rates of 11.3 percent for those 65 and over or 47.6 percent among those 85 and over derived from catchment area studies.[10] While all MADDE sample cases had some form of dementia, 68.4 percent had been identified with probable Alzheimer's disease at the time of referral into the demonstration. Table A6-1 shows tabulations of the DAT prevalence derived from the 1991-92 claims records of the MADDE sample. Requiring at least two claims with a qualifying DAT diagnosis substantially underreported the physician defined prevalence of this condition in the MADDE sample. Fewer than 19 percent of the sample met the Weiner and colleagues selection criteria of 2 or more DAT mentions in a single year. The majority of cases had either no claims in a single year or no claims with a single DAT diagnosis. A criterion of one or more DAT mentions brought the claims reported prevalence to 31.1 percent. Of those with no DAT mentions on their claims, 60.7 percent had been diagnosed with DAT by their referring physician at their enrollment into MADDE.

Insert Table A6-1 About Here

Case Classification and Selection Bias. The underreporting of dementia cases raises the issue of selection or observation bias. Is there a systematic difference between the cases with two or more DAT mentions in a year and those with one or no mentions? This issue is examined in Table A6-2 with a comparison of the mean expenditures associated with the DAT claims counts. Columns one and two show the mean annualized expenditures for those with less than six months of observation in a year and those with six or more months of observation. Cases are censored by death, HMO membership, and other attrition. Column three combines all cases into a single annualized mean expenditure estimate regardless of the length of exposure in the period. There was an average of 257 exposure days in this single year among the sample (s.d. 119.0 days).

As seen from these results, annualized expenditure levels are sensitive to the length of exposure. Periods of less than six months generally have annualized expenses at least a third higher than those of longer exposure. This is largely associated with higher cost among those who died. HMO enrollees generally had lower cost prior to such enrollment. More importantly for the comparison of dementia diagnosis counts, the number of observed dementia diagnoses is also associated with expenditures. Cases with two or more dementia claims counts have mean Medicare expenditures about 1.7 higher than those with no claims mentions of dementia when all cases are combined. The ratio is approximately the same whether the comparison is to those with less than six months exposure, six or more months, or all cases. Mean expenditures are about 25 percent higher comparing the two or more mentions group to those with just one mention.

The 1.7 ratio approaches the 1.9 ratio observed by Weiner and his colleagues[9] comparing DAT to nonDAT cases. The similarity in ratios is striking for two reasons. First, the MADDE comparison is between a subset of cases with DAT codes on claims relative only to cases that are known through physician referrals to have some form of dementia. This suggests that claims including a DAT diagnosis are for more costly care, on average, than the care received by those with dementia who are not flagged by a claims review. Second, neither analysis was adjusted for age (or other demographics). This is especially important in the Weiner and colleagues' analysis because the DAT group was substantially older than the nonDAT group: 17.7 percent of those with DAT were under age 75 (compared to 53.1 percent among the nonDAT group), 60.7 percent of their DAT cases were age 80 or over (compared to 25.4 percent among the nonDAT group). Age differences are important because age is highly correlated with the number and complexity of comorbidities. For example, the prevalence of DAT increases dramatically beyond age 80, as may encounters with the health care system for treatment of chronic conditions. Increased prevalence and encounters increases the likelihood of a DAT diagnosis appearing on two or more of Medicare claims. Related to this, disproportionate allocations of younger persons into the nonDAT group, may shift downward the mean expenditures for this group holding all other factors constant.

Expenditure levels are affected in another way by the case selection process: cases without claims cannot be classified as DAT or any other chronic condition. Unidentified (but true) DAT cases in this context have zero measured expenditures assigned to them, yet these cases would be included in the mean expenditure estimations for all individuals who have been classified into those without DAT. A DAT case, in contrast, in the current context had to have at least two qualifying claims. In the MADDE sample, over 6 percent (an average age of 79.3) had no Medicare claims in a 12 month period spanning 1991-92. More importantly, just over 60 percent of those classified as nonDAT because of no claims or no dementia mentions on claims, had been identified as having DAT by physician referral at the time of enrollment into MADDE.

Insert Table A6-2 About Here

Classifying Other Conditions. The patient classification problem illustrated here is not limited to the stringent dementia selection criteria or the restricted claims records used, nor is it limited to dementia. Table A6-3 shows the prevalence rates for dementia and a variety of other chronic conditions and how these vary comparing a single year of claims with prevalence counts derived over an average of 765.3 exposure days (s.d. 360.3). These counts use all Part A and Part B claims and <u>any</u> mention of the diagnosis. There is a striking consistency among the conditions: prevalence rates essentially double when comparing a classification from a single year to that over longer intervals. Also of note, while 100 percent of the MADDE sample is known to have dementia, the single year prevalence count identified just over half the cases with this condition. Similarly, a third were identified as having DAT codes in a sample where the DAT prevalence is 68.4 percent. The number of cases identified with DAT and the less stringent code of dementia began to approach, but did not reach the "true" prevalence, over two years of claims tracking.

Insert Table A6-3 About Here

Error in patient chronic disease classification derived from Medicare claims has implications for expenditure comparisons similar to those found for dementia. Table A6-3 shows two sets of mean annualized expenditures. One compares cases with a claims-based diagnosis in a year with those not identified as having the condition in that year. A second set of columns compares expenditures among those reported to have the condition at any time over the observation period and those not reported with the condition. Those with a condition, by definition, have had at least one. Those without a condition include both those without a claim for that condition and those who had no claims in the period. Those classified with a condition in a single year generally have double the annualized expenditures of those not classified with that condition. This pattern moderates somewhat when multiple years are used as the basis of classification and annualization, but cases

with a condition continue to reveal higher levels of expenditure. The most important difference in these tabulations is that average annualized expenditures for those with a condition diminish by about a third between the single year and multi-year classification. In contrast, the mean expenditures for those without the condition are rather constant over these periods. These results are not definitive because the true prevalence of a condition is not known. However, it appears that the use of a single observation year underestimates the prevalence of chronic health conditions, and identifies cases with annualized expenditures that are higher than the prevailing expenditures among those with the same condition, but who are not so identified in that period. It is also likely that a "regression to the mean" process may be operating here, namely that high cost cases in one year move toward the group's average expenditures over time.

Discussion

Age, gender, and institutional status have long been used by the Medicare program to partition the Average Adjusted Per Capita Cost (AAPCC) of the Medicare population into capitation reimbursement rates. This approach has been shown to over pay plans for healthier members, and to under pay for the more sick.[5,7] Except in very large and stable enrollments, these differences likely reward plans and providers who have been able to gain a favorable selection of members and penalize plans who attract and retain a more ill population. This situation produces an incentive for plans to under serve the ill so that they might elect to disenroll. An equitable risk adjusted reimbursement, at least in theory, will encourage plans to retain the more ill population.

The use of claims to obtain diagnoses seems to have emerged as one basis for adding health condition adjustments to capitation reimbursement rates. Weiner and his colleagues[9] extended this approach to the determination of risk-adjusted rates for those with Alzheimer's disease. A number of measurement issues complicate the accuracy of this process, especially if the case identification for risk adjustment is limited to claims data. An inherent problem is that claims records, even if compiled over several years, underreport chronic condition prevalence. Likely too (although not investigated here) is that the choice of a diagnostic code is influenced by payment incentives. Dementia may be particularly sensitive to such selection factors because this condition may be perceived as stigmatizing for the family or patient, and there has been little financial incentive for the provider to report this condition when rendering care for comorbid conditions. Claims-based case selection criteria under such circumstances may bias the prevalence rate downward.

The selection of diagnoses (such as dementia) from of a single year's claims may yield a sample of individuals with that condition for whom expenditures are biased upward. This occurs because diagnoses are reported in conjunction with treatment. For example, reported cases may be those with more frequent or costly service encounters, such as hospital stays and nursing home admissions. Those with the underlying condition, but who do not use services in that period are not classified with that condition. Analysis of MADDE program participants found that beneficiaries classified with DAT by a single year of claims had annualized expenditures that were 1.7 higher than those otherwise known to have DAT or other forms of dementia, but who had not been identified with this condition from Medicare claims in that period. Most of the MADDE sample with DAT were not identified from claims records during a single year. Differences in prevalence between a single year and multi-year claims tracking were observed for a variety of other chronic health conditions, as were differences in mean expenditures between those classified with and without the condition. In the short term, risk adjusted payment based on under reported prevalence may benefit providers as prevalence rates will likely increase as providers increase the use of DAT and other dementia diagnosis codes in response to a risk payment incentive. Increased reporting could occur even more rapidly if hospital's coders have been ignoring dementia diagnoses when compiling the submitted claims. (No information in the MADDE data identifies whether attending physicians included dementia diagnoses that were ignored on claims records.)

Under classification can be overcome to some extent by increasing the period over which claims are compiled. This issue has not received much attention in the literature. More commonly suggested supplements to claims-based classification include procedure codes, interview self-report, medical record reviews, or even physician reports.[5-7] One advantage of external data approaches over that from a short claims tracking period is that they further identify the presence or prevalence of chronic and other health conditions. Such data also open the option of multivariate condition risk adjustment typologies that combine functionality and conditions.[11]

A number of next steps for research are suggested by all this. At minimum it might be informative to replicate these analyses and those of Weiner and his colleagues on a data set where claims could be supplemented with interview or medical records. Such analysis could evaluate annualized expenditure differences between those with and without dementia (when dementia is known) and those with and without other chronic conditions and dementia. Panel data over several years is also desirable.

In the area of condition classification and risk adjustment, it is important to recognize that classifying a patient solely on the basis of having or not having a condition is only a starting point. Even assuming that classification was accurate with a condition such as dementia, there is the additional problem of isolating the cost attributable to that condition and that which may be associated with the management of other chronic conditions (e.g., coronary artery disease, congestive heart failure, diabetes, pulmonary disease). What portion of cost associated with dementia occurs due to poor management of one or more chronic diseases? How much of this cost is attributable to preventable problems?

Tied to the issue of care appropriateness is explicit consideration of whether patients are living in the community or nursing homes. This adjustment was not made by Weiner and his colleagues, nor was it reflected in the reported MADDE expenditure comparisons. However, the average monthly costs for the months preceding nursing-home placement have been tracked in the MADDE cohort of dementia cases. These reveal a marked expenditure increase in the weeks prior to such a placement. This pattern suggests that some combination of events contributed to either a hospitalization or a marked increase in outpatient costs. Were these events avoidable? Were they exclusively associated with dementia?

A limitation on most work attempting to find predictors of cost is that utilization and expenses

come from national or other samples that reflect the care received on average, not necessarily the most appropriate care for those with the condition. As shown by many others[12], variation among communities may prove to be informative in bracketing the benefits, risks, and potential expenditure savings of particular practice patterns. This could be done as risk adjusted rates are refined.

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Table A6-1
Individuals with Alzheimer Disease Diagnoses on Hospital Inpatient, Outpatient, and Physician Claims in One Year

	Number Eligible Cases	Percent of Those Eligible
No Claims	322	6.0
0 Mentions	3384	62.9
1 Mention	671	12.5
2 Mentions	367	6.0
3+ Mentions	635	12.6
Total cases	5379	100.0

Source: Medicare Alzheimer's Disease Demonstration unpublished Medicare Part A & B claims records. Inpatient, Hospital Outpatient, and Physician claims are used. Nursing home, home health, and hospice claims are excluded.

Table A6-2
Mean Annualized Medicare Expenditures by Number of Claims Mentions of Alzheimer's Disease in a Single Year

Count of Diagnosis Mentions	Annualization based on <6 months Mean	n	6 or more months Mean	n	Anytime in year Mean	n
None	$8634	1120‡	$4734	2586*‡	$5150	3706* ‡
One	11241	221	6551	450†	7102	671†
Two	10180	105	6345	262	6764	367
Three or more	17341	131	9470	504	10149	635
Two or more	14457	236	8403	766	8973	1002
All cases	$10691	1577	$6148	3802	$6619	5379

Source: Medicare Alzheimer's Disease Demonstration unpublished Medicare Part A & B claims records. Inpatient, Hospital Outpatient, and Physician claims are used. Nursing home, home health, and hospice claims are excluded.

* $p<.001$ for none vs. one comparison,

† $p<.01$ for one vs. two or more comparison.

‡ $p<.0001$ for none vs. two or more comparison

§ $p<.01$ or lower comparing the difference in expenditures across columns within each row, this is true for all rows.

// Column totals are based on the sum of rows 1-4. Row 5 is a subtotal combining rows 3 & 4.

Table A6-3
Occurrence of Selected Chronic Conditions and Mean Annualized Medicare Expenses when Conditions are Present or Not Present

	Year 1 Diagnosis Mention			Any Diagnosis Mention		
	% w/	Mean Expenditures		w/	Mean Expenditures	
Variable Name	Cond.	w/ Cond.	w/out Cond.	Cond.	w/ Cond.	w/out Cond.
Alzheimer's disease	33.9	$10459	$6732	57.2	$8317	$7807
Cancer (excludes minor skin cancer)	11.0	14925	7084	19.8	11595	7185
Cerebrovascular disease	22.6	14876	5803	41.4	11051	5843
Chronic renal problems	5.4	20990	7066	12.2	13618	7106
COPD / Asthma / Emphysema	14.2	16162	6565	26.9	11804	6695
Congestive Heart Failure	15.3	16067	6463	28.2	12472	6380
Coronary Artery Disease	19.5	13022	6710	33.3	11235	6439
Cerebrovascular aneurysm (CVA)	12.6	15870	6765	24.5	12262	6660
Degenerative nervous system conditions	15.2	13568	6950	24.8	12012	6709
Dementia	59.0	9820	5178	83.4	8244	7304
Diabetes (with and without complications)	14.7	12656	7174	22.1	11398	7135
Hypertension, any	30.3	10882	6557	46.5	9543	6655
Osteoarthritis related disorders	13.1	10942	7501	26.4	9513	7512
Osteoporosis	3.0	15061	7782	6.8	10362	7923
Peripheral nerve problems	2.2	17921	7771	5.1	12469	7829
Peripheral vascular disease	12.9	13547	7098	26.6	10952	6961

Source: Medicare Alzheimer's Disease Demonstration, unpublished Medicare Part A and B claims history files, all diagnoses from all claims are used. Expenses are annualized based on expenses incurred among both community dwelling and nursing home residents. Annualization is based on expenses divided by exposure days in fee for service care in the period, with the product multiplied by 365. Means are calculated weighting each case by its proportion of days of exposure in the period.

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